



HOSPICE CARE MINISTRY

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LESSON PLAN

Course Title: Hospice Care Ministry

Class Number: HC#0010

Prepared by: HCTI

Date Prepared: 07-03-10

Target Population: Hospice Chaplains

Total Hours: 20

Mandatory Grade: 72%

LESSON GOALS:

- To convey the importance of Hospice Ministry
- To explain the impetus for the training
- To acknowledge prior historical problems associated with hospice chaplaincy care
- To discuss the procedures necessary during a visit, death or crisis situation for the dying
- To explain the benefit of a hospice care chaplaincy

PRESENTATION:

It is the primary aim of this course that you develop awareness of the basics of hospice chaplaincy care through the use of this manual. As a Volunteer Chaplain, to effectively function in the hospice setting you must be able to:

- Understand the information obtained from the Hospice Ministry's manual
- Have a complete understanding of the skills necessary to be an effective Hospice Chaplain
- Remember that your ability to communicate successfully encompasses many complexities, skills, principles, and concepts
- Remember that the most important communication skill is your ability to exchange information, between you and the people you assist and serve, in a timely and effective manner

METHODOLOGY:

Definition: A body of practices, procedures, and rules used by those who work in a discipline or engage in an inquiry; a set of working methods.

It is our aim of to provide the basic training necessary for a Hospice Ministry.

It is not our intention to replace, override or persuade department, government or agency policy changes in any way. Our goal is to provide everything in this manual needed for you to begin your profession as a hospice care chaplain, however, we take no responsibility or liability for what a faith based hospice care chaplain does or how this material is used.

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PREFACE

This course is intended primarily for use by Chaplains and ministers who have the responsibility of providing professional and spiritual Hospice care for dying individuals and their families.

Our knowledge influences every aspect of our lives and our ministries and how we relate to others. Everything we do and everything we maintain about our actions should be rooted in God's word. Chaplains and Ministers, who provide hospice care and services, will benefit from this course.

The course will help encourage those who are already involved in hospice care ministry and and give a good faith-based insight into deepening their ministry through understanding the spiritual needs of the dying. The course exhibits a biblical view regarding what God tells us about caring for the dying with compassion and understanding.

The course has been designed to be used as a tool to assist the hospice care chaplain in understanding procedures associated with hospice care and ministry. The course is also a self study to be used and consulted as a resource in ministering to the dying and to encourage, stimulate and challenge the the hospice care chaplain.

Hospice Care ministries are becoming more common throughout the country; however, there is not yet a lot of written material for those wishing to start these types of ministries and unfortunately any knowledge gained, is gained through trial and error.

Faith Based Hospice Care Chaplains are not Doctors, Medical clinicians, Psychologists, or Psychiatrists and this manual is not intended to place any responsibilities or procedures for medical care or control of any kind, to any person or victim, upon the Hospice Care Chaplain.

Disclaimer of Liability: With respect to written material available from this course, the author makes no warranty, express or implied, including the warranties of merchantability and fitness for a particular purpose, or assumes any legal liability or responsibility for the accuracy, completeness, usefulness or misuse of any material contained in this manual.

It is our intent to provide this material for the faith based Crisis chaplain and those associated with the likeness of this profession.



MISSION STATEMENT

It is the mission of Homeland Crisis Training Institute to train chaplains & Ministers to provide a meaningful and life changing service to the communities in which they live and to provide support love and spiritual care to terminally ill individuals and their families through the phase of life and death.

It is our sincere goal to help chaplains and miniaters provide spiritual care for the dying as well as the living, and to help their families through the darkness of death to the richness of survival.

MODULE 1: A BRIEF HISTORY OF HOSPICE

Hospice care began from the European tradition of monks caring for travelers who became ill along their journeys. They were kept at monasteries until they recovered or succumbed to their illnesses. The medical care of the time was very limited and these illnesses often became life limiting. It is here that the roots of palliative (comfort) and hospice (end of life) care got their earliest beginnings.

In the 1960's, Dame Cicely Saunders founded the first modern day hospice in London, England. She was a physician with training as a social worker and nurse. Two major discoveries emerged from her program. One was Brompton's Cocktail, a mixture of several medicines that was given as an elixir for the relief of pain. The second came as a result of working in collaboration with psychologist Stanislaus Graf – the discovery of the importance of the holistic/psychological approach to the relief of emotional and spiritual suffering.

In the early 1970's the hospice movement made its way to America as an all volunteer service that provided care to people in the end stages of cancer who no longer responded to traditional treatments.

During the late 70's to early 80's the hospice movement had made its way to Florida. State Legislator Carrie Meeks, an African American, introduced legislation creating the first hospice services in the state of Florida. This bill would later serve as the model for the Medicare and Medicaid Hospice Benefits.

The monumental Hospice Medicare Benefit and its mirror in Medicaid were passed in 1984.

Operation Restore Trust scrutinized the administration of the Medicare and Medicaid Hospice benefits during the 1990's. Flaws were found in the way the benefit periods were arranged and revisions were made. As a result, the concept of palliative care was added to the hospice program.

Adding palliative care to hospice became a national movement that originated with the National Hospice Organization. The idea was to introduce the philosophy of hospice care earlier on in the course of a life-limiting illness and to extend this standard of care to the acute setting where recovery seemed a slim possibility and holistic support for the patient and family would be beneficial.

Today hospice care is offered to those suffering from a number of end-stage diseases such as congestive heart failure, chronic obstructive pulmonary disease, renal failure, Parkinson's disease, late stage Alzheimer's disease and other illnesses deemed life-limiting so long as a documentation of steady decline can be presented.

Hospice uses a team approach to care for people with life-limiting illnesses. The Hospice team includes professional staff, trained volunteers and the family and friends. Staff will include a medical director (physician), nurse, social services specialist, home health aide, chaplain, volunteer, grief support specialist and children's specialist, as needed.

The family and/or friends give most of the daily care to the patient. Hospice staff regularly visit to train the family on how to care for them, provide medical care, monitor medications to ensure pain and symptom control, assist with physical care as needed and offer emotional and spiritual support to the patient and family. Hospice nurses are on call 24 hours per day to assist patients and their families.

NOTES

MODULE 2: WHAT IS HOSPICE CARE?

When there are no more cures or a cure is no longer possible, hospice services provide medical, nursing, emotional and spiritual care. Hospice care is commonly provided by a coordinated team of professionals that may include a physician, nurse, home health aides, bereavement counselor, social worker and Chaplain.

Hospice is a program of care that is specifically designed to minimize suffering for dying patients and their family members. In the United States today, hospice is the only available comprehensive program to support very sick people at home. Hospice programs forego most diagnostic testing and life-prolonging treatments in favor of symptom relief, education of patients and family members about appropriate care, and comfort care.

Hospice care is always considered interdisciplinary; relying on a core team of physicians, nurses, social workers, home health aides and spiritual care providers. Hospice programs provide personal care for patients at home, in nursing homes, or in other care facilities. Although hospice personnel do not usually care for patients in hospitals and rehabilitation centers, many hospitals are establishing palliative care programs to address the same care issues.

Hospice programs differ substantially in the services they provide and in treatments and devices they use due primarily to the condition of the patient, hospice or hospital policy and procedure, and state regulatory law. Whether a particular patient and family should participate in the program depends on their needs and wishes, on their financial considerations, and on the skills and capacity of the local programs.

Nurses or aides ordinarily oversee and implement the general plan of care, including drug use, oxygen therapy, and IV lines or other special equipment. Nurses and aides are usually the first ones to assess and address needs. They can usually adjust drug doses and help obtain any new drugs or treatments.

Hospice physicians see patients when needed and share in shaping the plan of care. Social workers, chaplains, and volunteers help address interpersonal, spiritual, and financial issues. Chaplains and bereavement counselors support survivors through the grieving process. Hospice plans of care help family members prepare for the challenges of facing the death of a loved one and dealing with the situation at the time of death, including their role.

Most patients who are ill enough to require hospice care also require some assistance with daily activities (e.g. dressing, bathing, preparing food), and some may be completely dependent. Family members and friends often provide this care, but additional help from home health aides and volunteers may become necessary.

Medicare or insurance typically pays a per diem rate that is intended to cover all hospice services, including a negotiated amount of help from home health aides, but only after a physician certifies that the patient has a fatal disorder with a life expectancy 6 months or less.

Physicians may be reluctant to use hospice care because a treatable condition could develop. However, this reluctance may not be justified because many treatable conditions are within the scope of hospice care, and patients also can leave hospice at any time and re-enroll later.

During hospice care a loved one is cared for at home, normally in the last few months, weeks, or days before death. Many people think of “Hospice” as a place where terminally ill patients are sent; this is not always the case. The roots of the term hospice actually come from the medieval concept of providing rest and comfort to the sick and dying.

Hospice personnel believe in the notion of palliative care, which emphasizes the improvement of the quality of life. Instead of trying to extend life, a Hospice care plan seeks to enrich and fill the days before death with peace and comfort.

Patients are not the only focus point of palliative care. Hospice care professionals and volunteers will come to the home to provide solace and comfort for them and their families. Hospice care seeks to ease the pain of the sick, while giving them (and their families) physical, spiritual, social, and emotional support.

Some patients may be in extreme pain during the death process. It is possible that they may make discomforting sounds and noises, and they may even appear to be having difficulty breathing. They may not realize who family members are or where they are in their final moments. While the family could be imagining a peaceful death, with the patient just slipping away, the reality may be much more confusing, upsetting or scary.

A hospice nurse or chaplain can help explain and prepare the family for what is going to happen. The end of a loved one’s life may be extremely difficult, but hospice chaplains and workers are incredibly lovely and calming people. They can be extraordinarily helpful during this difficult time.

Hospice is a comfort, compassion and empathy-based care, and support for terminally ill patients and their families. Hospice focuses on caring, not curing. It emphasizes quality of life, helping patients live fully with the most comfort for as long as possible. Hospice neither hastens nor prolongs death. Hospice services attend to the physical, emotional and spiritual needs of patients and families with a unique team approach that brings in a wide range of resources and disciplines.

HOSPICE CARE IS:

- Physician directed, nurse managed
- Focused on comfort and coordination of care, rather than on cure
- A concept of care that meets the physical, emotional and spiritual needs of those living with life-limiting illnesses
- An interdisciplinary approach that improves quality of life from diagnosis through the end of life and bereavement

- Provided by health care professionals with the highest levels of certification available in this specialized field

THE HOSPICE TEAM

Medical Director: The Medical Director consults with the teams caring for patients, offering medical guidance and oversight to the plan of care.

Hospice Physician: Hospice Physicians consult with patients' primary physicians to determine each plan of care. The hospice physician makes house calls and determines which medications and treatments will offer the best quality of life.

Nurse Case Manager: The Nurse Case Manager is a Registered Nurse (RN) who manages patients' pain and provides symptom control. The preferred case load for each nurse is 15 to 20 patients.

Psychosocial Counselor: Counselors serve as social workers who provide patients and families assistance in finding financial and emotional resources. They facilitate communication and support families with counseling.

Chaplain: Nondenominational chaplains provide spiritual support to patients, caregivers and families, often serving as liaisons between them and their religious community. If patients do not have a church affiliation, chaplains can take a more primary role through visits and prayer. Chaplains often assist with memorial services and funeral arrangements.

Certified Nursing Assistant: CNAs provide assistance with the personal care needs of the patients. They help patients bathe and dress and help with household chores as well.

Volunteers: Volunteers support patients and caregivers in less traditional roles, such as providing respite for a caregiver, running errands, befriending patients and simply being in the home to listen.

Clinical Pharmacist: The clinical pharmacist provides end-of-life pain and symptom management. The pharmacist may recommend therapies and create medication plans with the nurse and physician and provide education to caregivers

PALLIATIVE CARE

All hospice care is palliative in nature. The word *palliate* comes from the Latin word *pallios* which means "to cloak" or "to mask", referring to the alleviation of pain and other symptoms.

Palliative care is defined as *the active compassionate care of the chronically and terminally ill, primarily directed towards improving the quality of life at a time when the goal is not cure*. The emphasis of palliative care is on the control of pain and other symptoms, and meeting physical,

emotional, spiritual, social and cultural needs. It is multidisciplinary in its approach, encompassing the person, family, caregivers and the community in its scope and extends to include grief and bereavement.

The need for palliative care may occur at any time in the patient's illness. Control of symptoms and psychological support are important aspects of active disease-oriented therapies. For the patient who has not responded to treatment, symptom control and quality of life are central aspects of end-of-life care.

The term "supportive care" is often used to describe symptom control and treatment of side effects in a continuum of curative and palliative therapies. They define supportive care as concern with the optimal well-being of the patient in all stages of disease.

There are numerous national and international associations of palliative care (e.g., The American Academy of Hospice and Palliative Care Medicine). For the purposes of this chapter, palliative care is defined broadly to include patient care from diagnosis to death.

Many countries, including Great Britain, France, Canada, Australia, Japan, and the Philippines, have made palliative care an integral aspect of their government-supported cancer control programs. In this way, they have demonstrated a strong commitment to addressing the care of the dying.

In the United States, increased attention has focused on the inadequate provision of humane compassionate care at the end of life. A recent Institute of Medicine report outlines the problems, explores the issues, and provides a series of recommendations arguing strongly for the need to improve the care of the dying.

Palliative care in teams improves outcomes for patients compared with the outcomes of conventional care in many areas; including the amount of time spent at home by patients, satisfaction of patients and their caregivers, symptom control, the number of in-hospital days, overall cost, and the likelihood of dying in the locale preferred by the patient.

END OF LIFE SERVICES

A proclamation issued from the White House in November 2006, in recognition of National Hospice & Palliative Care month, reads in part: "Hospice care enables many of our citizens to spend their final days in comfort and dignity surrounded by loved ones. This palliative care plays a vital role in our Nation's health care system, and the dedicated work of hospice caregivers helps ensure that our citizens receive the services and support they need."

The National Hospice and Palliative Care Organization's facts and figures for data collected in 2006 showed the following:

- The average length of service is 59.8 days.
- The median length of service is 20.6 days.

- The number of hospice programs grew from 4160 in 2005 to over 4500.
- At 44.1 percent, cancer diagnoses continue to account for less than half of all hospice admissions.
- One in five patients is of a minority race; patients classified as multi-racial rose to 8 percent, vs. 6 percent in 2004.
- Twenty percent of hospice programs actively provide or are developing pediatric palliative care programs.
- Approximately one-third of all deaths in the United States were under the care of a hospice program. The 1.3 million hospice patients served includes 870,000 who died, approximately 210,000 patients who were admitted in 2006 but carried over to 2007, and approximately 220,000 who were discharged alive.

Hospice is not a place but a philosophy of care created to help people live with dignity, comfort, and compassion at the end of life.

Many organizations across the nation host activities to educate the public and other healthcare providers about quality end-of-life care. The goal is to put a *face* on quality end-of-life care – the faces of nurses, doctors, social workers, spiritual caregivers, homecare aides and volunteers who provide services and support to families during one of life's most challenging times.

When a patient is receiving hospice care the patient is in control and hospice will try to follow the patient's wishes. Hospice enables and encourages family and friends to participate in the end of life care. Most importantly, hospice offers counseling before and after the loved one's death and advice and aid to caregivers who may suffer both an emotional and financial toll.

NOTES

Module 2

Hospice Manual

Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. _____ of hospice programs actively provide or are developing pediatric palliative care programs.
2. Hospice is not a place but a _____ created to help people live with dignity, comfort, and compassion at the end of life.
3. All hospice care is _____.
4. The need for _____ may occur at any time in the patient's illness.
5. Hospice is a program of care that is specifically designed to _____
_____.

MODULE 3: WHAT IS DEATH?

Ideas about what constitutes death vary with different cultures. In Western societies, death has traditionally been seen as the departure of the soul from the body. In this tradition, the essence of being human is independent of physical properties. Because the soul has no physical manifestation, its departure cannot be seen or otherwise objectively determined; in this tradition, the cessation of breathing has been taken as the sign of death.

In modern times, death has been thought to occur when the vital functions cease; breathing and circulation (as evidenced by the beating of the heart). This view has been challenged, however, as medical advances have made it possible to sustain respiration and cardiac functioning through mechanical means. Thus, more recently, the concept of brain death has gained acceptance. In this view, the irreversible loss of brain activity is the sign that death has occurred. A majority of the states in the United States had accepted brain death as an essential sign of death by the late 1980s.

Even the concept of brain death has been challenged in recent years, because a person can lose all capacity for higher mental functioning while lower-brain functions, such as spontaneous respiration, continue. For this reason, some authorities now argue that death should be considered the loss of the capacity for consciousness or social interaction. The sign of death, according to this view, is the absence of activity in the higher centers of the brain, primarily the neocortex.

Society's conception of death is of more than academic interest. Rapidly advancing medical technology has raised moral questions and introduced new problems in defining death legally. Among the issues being debated are the following:

- Who shall decide the criteria for death, physicians, legislatures, or each person for him or herself?
- Is advancement of the moment of death by cutting off artificial support morally and legally permissible?
- Do people have the right to demand that extraordinary measures be stopped so that they may die in peace?
- Can the next of kin or a legal guardian act for the comatose, dying person under such circumstances?

All these questions have acquired new urgency with the advent of human tissue transplantation. The need for organs must be weighed against the rights of the dying donor.

As a result of such questions, a number of groups have sought to establish an individual's "right to die," particularly through the legal means of "living wills" in which an individual confers the right to withdrawal of life-sustaining treatment upon family members or legal figures.

THE DEATH SYSTEM

The death system in any given society has a number of components. First, people are connected to the “death system”. Because death is inevitable, everyone will, at one time or another, be involved with death; one’s own or another’s.

Other individuals have more regular roles in the death system, earning their livelihood primarily by providing services that revolve around death. These include coroners and funeral directors, persons involved with life insurance, and florists.

In other cases, the role may be apparent. Anyone, for example, involved in food manufacturing, especially meat, and food service, depends on the slaughter of animals. Clergy, police, firefighters, and health care workers all interact with the dying, dead, and bereaved and therefore have roles in the death system. Even statisticians who create actuarial tables play a role in the death system.

A second component of the death system is places. Places include hospitals (though they do not have the prominent role that they once had as places people go to die, at least in industrial societies), funeral homes, morgues, cemeteries, and other places that deal with the dead and dying. Memorials and battlefields are also places associated with death. Such places need not always be public. Family members may harbor superstitions or simply memories of a room or area where a loved one died.

Times are a third component of the death system. Certain holidays like Memorial Day or Halloween in U.S. culture, the Day of the Dead in Mexican culture, or All Saints' Day or Good Friday among Christian traditions are associated with a time to reflect upon or remember the dead. Again, different cultural groups, family systems, or individuals may hold other times, such as the anniversary of a death, battle, or disaster, as times to remember.

Objects and symbols are the remaining components of the death system. Death-related objects are diverse, ranging from caskets to mourning clothes. Symbols too are diverse. These refer to rituals such as Catholic "last rites" or funeral services, and symbols such as the skull and crossbones that warn of or convey death. Because language is a symbolic system, the words a society uses to discuss death are part of the death system as well.

FUNCTIONS OF THE DEATH SYSTEM

Every system or structure within a society survives because it fulfills manifest and latent functions for the social order. Change occurs when the system no longer adequately fulfills its functions, due, for example, to changing social conditions, or until innovations emerge that better address these functions.

Warning and predicting death: This function refers to the varied structures within a society that warn individuals or collectives about impending dangers.

Examples of organizations that fulfill these functions include weather forecasting agencies that may post warnings, media that carries such warnings and emergency personnel who assist in these events. It also includes laboratories and physicians that interpret test results to patients.

Caring for the dying: This category offers a good example of cultural change. The hospital was seen as ineffective by many in caring for the dying, so new cultural forms such as hospice and palliative care emerged to fulfill these functions.

Disposal of the dead: This category includes practices that surround the removal of a body, as well as the rituals and methods of disposal. Being that every culture or generational cohort has its own meaningful ways to dispose of the dead, this can lead to strains when cultures differ.

Social consolidation after death: When an individual dies, other members of the society, such as the family or the work unit, have to adjust and consolidate after that death. In the Middle Ages, the guild system, that included masters (i.e., skilled and experienced professionals), intermediate-level journeymen, and beginning apprentices, served to mediate the impact of often-sudden death by creating a system that allowed for constant replacement.

In industrial society, retirement removes workers from the system, lessening the impact of eventual death. In American society, funeral rituals and spontaneous memorialization, self-help and support groups, and counselors are examples of other structures that support consolidation.

Making sense of death: Every society has to develop ways to understand and make sense of loss. One of the values of funeral rituals is that they allow for a death to be interpreted within a given faith or philosophical viewpoint.

Killing: Every death system has norms that indicate when, how, and for what reasons individuals or other living creatures can be killed. There are international treaties that define what weapons and what killings are justifiable in war. Different cultures determine the crimes an individual can be executed for as well as the appropriate methods of execution. Cultures, too, will determine the reasons and ways that animals may be killed.

Death systems are not static: They constantly evolve to deal with changing circumstances and situations. For example, the terrorist attacks of September 11, 2001, have led to the development of whole new systems for airline security that include new personnel, regulations, screening and identification.

As causes of death have changed, new institutions such as hospice and nursing homes have developed. A series of social changes, such as demographic shifts, historical factors (i.e., the development of nuclear weapons), and cultural changes (i.e., increasing diversity), have led to the development of the death studies movement.

Because it is a related system, changes in one part of the system are likely to generate changes in other parts of the system. For example, the growth of home-based hospice has led hospitals to reevaluate their care of the dying; contributing to the current interest in palliative care.

Thanatology (the study of the medical, psychological, and sociological aspects of death and the ways in which people deal with it) is often more focused on the clinical, stressing the needs of dying and bereaved individuals. While the concept of the death system has not received widespread attention, it is a powerful reminder of the many ways that death shapes the social order.

TWELVE PRINCIPLES OF A GOOD DEATH

Twelve principles of a good death were identified in *The Future of Health and Care of Older People* by the Debate of the Age Health and Care Study Group. They are:

- To know when death is coming and to understand what can be expected
- To be able to retain control of what happens
- To be afforded dignity and privacy
- To have control over pain relief and other symptom control.
- To have choice and control over where death occurs (at home or elsewhere).
- To have access to information and expertise of whatever kind is necessary.
- To have access to any spiritual or emotional support required.
- To have access to hospice care in any location, not only in a hospital.
- To have control over who is present and who shares the end.
- To be able to issue advance directives which ensure wishes are respected.
- To have time to say goodbye, and control over other aspects of timing.
- To be able to leave when it is time to go and not to have life prolonged pointlessly.

These principles are good ones to incorporate into health care services, professional codes and care plans or missions for end of life care organizations and institutions.

“A good death was a peaceful death.”

- The dying person had finished up all of his or her business.
- The dying person had made peace with others before his or her death.
- The dying person was at peace with his or her own death.

A good death is one that does not occur as a result of:

- Violence
- Accident
- Fearsome disease
- Foul play

DEATH IN HOSPICE CARE

It is common today to conceptualize death through the stories provided by modern medicine. The language and metaphors by which death was traditionally spoken of, as a challenge, as life's last great act, or as a transition to another world have given way to the materialist metaphors of modern science.

One speaks about terminal illnesses; about dying of cancer, dying of AIDS, dying of heart disease and one relates to mortality through these concepts. Distance from death can be 'gauged' through T-Cell counts, cholesterol levels, blood pressure measurements, and, undoubtedly sooner than we think, through genetic tests of various kinds.

There have been a number of responses to the desperate conditions of high-tech dying, such as the development of legal wills, the growth of advocacy, and the vocal critique of 'right to die' movements that have led to the institutionalization of voluntary euthanasia in the Netherlands and for a time, in the Northern Territory of Australia. Without a doubt, the most successful challenge to the medicalization of death has come from the hospice and palliative care movement.

Over the past thirty years in North America, hospice has grown to offer an important institutional alternative to the depersonalized experience of high-tech dying. Rather than focusing on curative interventions, hospice attempts to provide relief from the pain associated with death.

WHY SHOULD WE THINK ABOUT DEATH?

Although we are certain of death as a fact, we are uncertain of its meaning and of the process that unfolds "behind the scenes." Most people, therefore, tend to avoid dealing with the issue at all; sometimes expending considerable psychological energy to keep it below the threshold of consciousness. Then, when they are confronted by its impending inevitability, fears are doubled and often accompanied by other unpleasant emotions.

This is all energy that could be put to better use. If we view death as a beginning, necessary to prepare for a re-birth and as a change in consciousness through the removal of limitations, then death becomes more of a desirable event than a threat.

The aim of hospice is not only to help one die peacefully, but to "live until you die." An aspect of the hospice movement that is often overlooked, in favor of its achievements in pain and symptom reduction, are the stories it tells of the dying process. One of the reasons that hospice has been so successful is that it offers uplifting and inspirational stories with which to make sense of death. Not only do these stories inspire but they guide. They are moral tales, encouraging individuals to move through the dying process rather than fight it at all costs.

Certainly, to speak of dying as a personal "journey," as is frequently the case in hospice narratives, rather than a "pathological" process, suggests a different normative orientation towards the end of life. It also reflects a different understanding of whom, ultimately, ought to be

in control of the dying process. Such representations work to trouble, at least in a limited manner, the medical appropriation of death.

The contributions of hospice not only offer compassionate end of life care but dignified spaces in which to die while operating on a cultural level. It is an interpretive intervention. Hospice care has gone a long way to ameliorating the care of the dying. Yet, it offers only one alternative to dealing with dying and a limited set of interpretations to help people through this process.

Death is conceptualized through a variety of methods: narratives, metaphors, tables, charts, films, photographic images, paintings, etc. The term “representation” is used to refer to these diverse forms of interpretation.

The concept of representation is useful as it emphasizes the social processes through which meaning is made. Further, by acknowledging that there are different ways of representing reality, the concept opens up ontological questions to do with what aspects of reality are brought to light and normative questions to do with how these might influence behavior.

While death does not ‘exist’ as a skeleton walking among us, this artistic representation draws attention to death’s unpredictable nature and succeeds in conveying a certain truth: that for many, regardless of age, death often comes as a surprise. This representation also suggests a specific normative orientation towards mortality. Indeed, by pointing to the always present possibility of death, it encourages people not to take life for granted.

Representations of death are not confined solely to the arts. To date, some of the most compelling explorations of the various modes of representing death are to be found in the analyses of medical knowledge.

Scholars within medical anthropology, sociology, communications and cultural studies have noted that scientific medicine is not only a technical endeavor but a cultural one as well. Medical knowledge provides a number of models and metaphors for the interpretation of death and, stemming from these, a set of strategies for managing mortality.

The concepts of “pathology” and “risk” are among the most significant in shaping the contemporary understanding of death. Thinking about mortality through the framework of pathology, for instance, structures death in a number important ways.

The concept of pathology serves to shatter the ubiquity of death by fragmenting it along causal lines into a multitude of individual occurrences of “disease.” Indeed, it could be argued that the pervasiveness of the disease metaphor has led to the frequent and mistaken belief that we live in a death denying culture. It would be more accurate to say that the pathological interpretation of death has transformed dominant responses to mortality. Far from resulting in denial, it has legitimated the expenditure of considerable time, energy, and capital in the effort to identify and avoid causes of death.

When death is represented in terms of pathology, a further transformation occurs. Death becomes an object of medicine; it is medicalized. One of the key features of medicalization is the transfer of authority from previously non-medical domains to the medical community.

Rather than the clergy or the dying person presiding over her or his death, knowledge of death and determinations of appropriate courses of action come to be seen as falling largely under the jurisdiction of the medical profession.

Recent intensification of this medical/materialist paradigm has enabled physicians to technically determine the exact ‘moment’ of death. No longer is death a figure with whom we dance throughout life, but a temporally bounded and physically contained micro-event in the brain.

This manner of representation has had profound normative implications, not least permitting the legal harvesting of organs from warm, ‘breathing’ bodies and encouraging the development of transplantation as a strategy of life-extension.

There is no proper, right or wrong way of representing death in a manner that does not miss certain dimensions of its reality or reflect interests or incline one’s attention and action in certain ways. None of this is to suggest, however, that the effects of particular forms of representation operate in a deterministic manner.

It is possible to speak of terminal illness and still accept death and wonder at its mysteries. It is also possible to see dying as an opportunity for learning, yet wish to avoid death. While particular modes of representation are not deterministic they set limits on and exert pressures around what is possible to think and what constitutes rational action.

THE NATURAL DEATH

The discourse of hospice care is characterized by frequent reference to the ideal of a *natural* death, a gradual passing away unmarred by fear, denial, or technological encumbrances. The representation of the natural death owes much to the work provided by the passing of a time when death was familiar and accepted.

The period of the “tame” death was replaced by one in which death appeared “wild” and dangerous, needing to be contained by medical intervention. Central to the idea of a “natural” death is the minimization or absence of technology. Hospice imagery is characterized by the absence of high tech devices when possible.

Many discussions with hospice workers indicate that an important difference between modern medicine and the culture of hospice lies in the way nature is conceptualized. The core of modern medical practice lies in the Cartesian belief that the human body can be treated as if it were a machine. The machine metaphor also shapes the understanding of human mortality. Within the mechanical paradigm, death comes to be represented as a breakdown of the body-machine, and dying is perceived to begin at that point where nature’s disorder outstrips the technical capacity

for intervention. Individual deaths are, therefore, often spoken of as if they were the result of a physiological “failure”.

In contrast, organic notions of the body often underlie the interpretation of death within hospice culture. Organic modes of representation characterize nature as a living, interconnected and intentional organism. Thus, the human body is represented as an organism imbued with agency and purpose.

To say that dying is natural, in this context, gives it an entirely different normative valence than to represent it as the result of a breakdown. To say that it is natural is to mean that death is supposed to occur. It is a process that the body intends, is prepared for and is capable of achieving.

The following description conveys this representation of the dying body as an intelligent and purposeful organism:

“Your body is so wonderful, for anyone who is going through a gentle dying process. The body chemistry changes, just as it does at birth. The person who is dying usually starts to lose interest in food, then not only foods but liquids. They no longer feel thirst. As the body becomes dehydrated the endorphins, like you get in a runner’s high, start to be released in the body so it creates a calming effect, a sort of euphoria.”

In the above statement, the body is not only depicted as an intelligent body, willfully undergoing the process of dying and changing in preparation for death, but it is also a compassionate body, releasing “endorphins” to relieve discomfort; the “euphoria” and the analogy to a “runner’s high” place this representation at a distance from that of a “failure” or “breakdown.” More importantly, one senses a profound trust in the body’s capacity to die and to die peacefully in the majority of cases.

DEATH / BIRTH

Many professional caregivers feel the emotional challenge of their work but also feel that it is immensely rewarding. The possibility of accompanying someone through the end of life, perhaps holding their hand as they take their last breath, is a privilege.

A common dilemma noted by many hospice care workers, however, is conveying the power of this experience to those with little or no knowledge of dying. Analogies to “birth” and the “miracle of life entering the world” are often employed to give some sense of what it might be like to witness life leaving. The concept of “birth” thus serves as a conceptual bridge, providing a common ground for shared meaning to be constructed.

The concept of “birth” shapes the understanding of death in a number of ways. On the one hand, the act of giving birth is the archetypal “natural” act. The use of the concept thus furthers the representation of the body as an organism with an innate capacity to die (e.g. “The body chemistry changes, in death, just as it does at birth,”).

On the other hand, the birth of a child is easily understood as an awe-inspiring experience. The analogy to birth thus encourages one to consider the mysterious and beautiful dimensions of dying: Death, in many cases, can be very beautiful; just like birth is beautiful, it's a rite of passage, so death is beautiful.

The ability of the birth metaphor to powerfully represent death as a magical experience, one that is essential to life, is also useful for hospice nurses who sometimes struggle to find adequate words to convey the privilege of their role as care providers.

Increasingly, the term "midwife" is used by hospice care workers as a manner of characterizing their work: Hospice is now considered as "midwives" to the dying; given as an individual interpretation, the concept of "midwives to the dying" as "midwives to birth" works really quite well to express the gentleness and the celebration of life even in death.

THE CYCLE OF LIFE

Questions to do with "why" things occur are displaced by questions that ask "how" things happen. This transformation is reflected in the contemporary belief that understanding death means knowing "how we die". Dominant explanations for death in such narratives are causal, pointing to the effects of pathologies, risks, and accidents.

While the interpretation of mortality through the metaphors of "pathology" or "risk" may be a necessary logic for a system of thought geared towards the avoidance of death, it likely impedes the care of the dying. Not least, hospice care workers note that the connection between death and disease heightens anxiety.

Death doesn't need to be somber. It doesn't need to be scary. It doesn't need to be fearful. But man has created all this. It's all cancer and heart disease. It's all fear and worry. Further, thinking of mortality through the metaphors of "disease" and "risk" frames each individual death as somehow "abnormal," "unnecessary" or "premature." Within this perspective, the ethical or healthy response to mortality is to engage in the rituals of avoidance that curative medicine offers.

The interpretation of death as part of a cycle is important, for it draws attention away from questions to do with how people die. It suggests, instead, answers to the question of why they die. From this perspective, people die because it is through the ongoing cycle of birth and death that the human species reproduces itself. Locating death within a cycle of life provides a rationale, a justification for dying. As part of a cycle, mortality becomes meaningful and death purposeful, even to the nonreligious.

The representation of death as part of a cycle may serve as a source of healing in itself. The following story, told by a director of pastoral care, illustrates the healing that may be afforded when death is interpreted as part of the cycle of life:

“The situation involved a lady who had no religion who was basically agnostic.... I came in and for the next few weeks I visited with her. She told me about her life, and about her husband. Anyway, it was during the spring time and she had told me how much she loved daffodils and just at that time at the place where I was living I had a little garden and, of course, daffodils were coming in. And so I cut her some daffodils and brought them in. I put them in a vase and brought them in for her. She was just delighted. And then she talked to me about how beautiful the flowers were but that they would fade and then they would die—you know they were cut—but even flowers in the ground would fade and die through the seasons. It was nature and she accepted this, and she accepted the fact that she was going to die and she was fine about it, because she had known love, she had known her husband, she had known other people who were significant in her life. And then she said, ‘And for what it’s worth I’ve seen something in nature, which if you want to call it God it might be God, I knew it was something greater than just me.’ And she said ‘whatever it is, I’m at peace.’”

GROWTH

In order to illustrate the benefits of the hospice care approach, hospice workers frequently tell stories that describe the dying process as offering a number of opportunities, such as the chance to strengthen family bonds, to put one’s life in perspective and to deepen spiritual awareness. These narratives illustrate a most important re-interpretation within hospice, whereby death is symbolically transformed from a time of physical “decay” to an opportunity for “growth.”

In narratives of growth, dying is represented as a “challenge.” It is a time punctuated by various threats, hazards, and difficulties, which, if courageously faced and successfully overcome offers the possibility to learn valuable lessons and to grow as a person. Growth is represented as occurring along a number of lines; personal, interpersonal, spiritual, existential, and emotional. It allows for the growth of others, as well.

The end of life is a time of growth for the individual who is experiencing the actual process of dying, it is a time of growth for his family, friends, support system, significant other, and, indeed, the entire community which is the context for the person.

The importance of the metaphor of growth as a way of thinking about death is hard to overstate. Growth opposes the conception of death as a “problem.” Instead, stories of growth draw attention to the positive dimensions of dying. This is not without significant normative implications. The possibility of growth suggests that one ought to try and overcome difficulties rather than avoid them. It inspires hope and implies that suffering may not be pointless.

The metaphor of growth also removes death from the confines of the body. Dying is no longer represented as a “disease process” that transpires, mechanically, deep within human flesh nor is it accessible only to medical professionals through specialized diagnostic technologies. Instead, the metaphor of growth represents dying as a process that is “lived.” It is a process that lay people participate in and may shape.

In a reversal of notions of failure, the hospice vision portrays dying as a positive act of transformation. Indeed, in narratives of growth, the dying person and his or her family are often represented as having a moral obligation to act and to make the most of this “last chance for living.” Dying will only be an opportunity for growth if all these various people engage it as such. If they disengage or they try and deny it then growth is not going to happen.

Somewhere down the line, the dying person accepts that as a reality and rather than trying to fight it, does everything possible to make it a positive experience, utilizing the time to do those things that they need to do; reaffirm the family ties, maybe put closure on unfinished business, tidy up financial affairs or legal affairs, maybe even plan their own funeral or memorial, or whatever is to happen to them, and then just enjoy the time with friends or their relatives, perhaps make peace with God, or revisit what it is they exactly believe about God or about life.

JOURNEYS

Within hospice the dying process is frequently spoken of as a “journey.” This reflects not only the belief that the end of life is an open field of possibilities but the belief that the dying person is an active participant in the process.

The connection between death and journeying is an old one. It dates back at least to ancient Greek civilization where the dead were believed to journey across the river Styx to their final resting place. The metaphor also parallels the Christian teaching of dying as a “passage” to an otherworldly existence in either Heaven or Hell.

However, for most people the journey is generally situated within life rather than after death. While this secular use lends the metaphor certain versatility, it does not necessarily exclude the possibility of an afterlife. On occasion it is used to suggest a transition to another “plane of existence”.

The journey metaphor is also frequently employed to describe the work of the care providers, acknowledging that by accompanying the dying they too are undertaking an emotionally and spiritually challenging endeavor.

Experiencing the death of a loved one is one of our most difficult, complex and profound personal journeys. For those who have chosen hospice care as a profession or as volunteer work, the daily journey taken with others and with oneself is a deepening experience that brings one face to face with the core of life.

While the metaphor of a journey may be hastily dismissed as a euphemism, it is important to note how it moves the conception of death away from the negative, the frightening, and the uncontrollable. Instead, the metaphor frames the difficulties encountered as a test of personal character, courage, and willpower.

It further suggests that striving to surmount or to make the most of these difficulties is purposeful; a tacit assumption being that the journey has a meaningful destination. The

representation of the dying person as “an individual on a quest” thus provides an inspiring way to interpret one’s position in the face of death. Indeed, it frames the dying person as the one ultimately in charge of negotiating the dying process.

This perspective may therefore be viewed by some as contesting the authority the medical community has gained over death and, specifically, over the determination of appropriate responses to mortality. However, the metaphor does not deny a role for either medicine or hospice. By framing the end of life as a difficult and uncertain territory, an important task for hospice is to guide people through this land.

THE LIMITS OF OPTIMISM

There is no such thing as a total perspective that captures all facets of reality. All knowledge is partial. As a consequence, while partial perspectives might offer powerful ways of seeing and acting in certain limited situations, they become dangerous when over-generalized, universalized or taken for granted. Given this, one of the key tasks of critical scholarship is that of holding knowledge accountable for both “its promising and its destructive monsters”.

Hospice care’s vision of death is both appealing and optimistic, certainly one of the reasons the movement has been so successful in recruiting staff, volunteers, and public support for its expansion.

Without a doubt, in the context of a culture where death is feared or systematically avoided through life-extending practices and strategies of risk management, hospice culture offers a promising way of thinking: providing inspiring interpretations that encourage individuals to confront death and move through the dying process.

However, the faith in human progress that has played such an integral role in legitimizing medicine’s war on death is implicit in some, though certainly not all, of the optimistic interpretations encountered in hospice culture.

The metaphor of “growth” is particularly problematic in this regard. While inspiring narratives of growth and the possibility of “dying well,” it may also be viewed as a continuation of the hope that if one just approaches death in the right way, with the correct knowledge, it may be mastered. In this case, death is not avoided but made meaningful.

The framework of optimism provides a limited vocabulary with which to speak of the darker side of death. To be sure, meaninglessness, suffering, and chaos are found in hospice narratives. However, all too often, they take on a temporary existence. Optimistic representations frame them as a “challenge” to be overcome, a “task” on the route to growth.

A recent editorial by David Roy (2001) in a major hospice journal offers a case in point. Roy calls for the need to attend to the “shadow side” of death. Yet, the editorial is framed by the possibility that one can “suffer up” and move through this moment towards some deeper (though vaguely specified) connection with “living”.

Of course, there is truth to this. In certain situations, people do learn through suffering. However, when over-generalized, the metaphor becomes ideological. It thereby obscures another truth: that for some individuals dying may ultimately be a meaningless experience or growth at the end of life; tiring, trivial, or too little too late.

Patients and their families know the surprising truth about dying. This stage of life holds remarkable possibilities. Despite the arduous nature of the experience, when people are relatively comfortable and know that they are not going to be abandoned, they frequently find ways to strengthen bonds with people they love and to create moments of profound meaning in their final passage.

The claim to the discovery of a generalized truth limits the ways in which one may legitimately think about and approach death. As an antidote to such thinking, it would help to switch metaphors from discovery to interpretation.

The hospice movement has worked to ameliorate the care of the dying, in part, by operating on a cultural level, challenging the dominance of biomedical representations and offering an alternate set of interpretations. It has, in effect, broadened the range of legitimate narratives and metaphors that one may use to conceptualize death. There is little to be gained by affecting another form of closure.

The degree to which it is possible for a community that is primarily concerned with improving the care of the dying to simultaneously bear witness to meaninglessness and anguish and to do so outside of a common logic is worth questioning. If only to draw attention to the need to avoid the formation of another monopoly of knowledge and to remain continually open to other interpretations of death and other approaches to dying.

Representations of death have important implications for the manner in which individuals approach dying and societies manage mortality. While the hospice movement has contributed significantly to pain and symptom management and has helped raise awareness of the need for better terminal care, it has also contributed by providing alternate forms of interpreting death.

The representations offered by hospice envision dying as a difficult but natural stage in which meaningful living is possible. They encourage individuals to move through the dying process and draw attention to beauty and mystery in a stage of life otherwise feared.

In light of a culture that conceives of death in the negative and a medical community that represents dying as a pathological process, such inspiring interpretations are urgently required. However, to the degree that they may forgo an exploration of futility or silence other voices, the metaphors provided by hospice may simultaneously reflect a continuation of efforts to rationalize and master human mortality.

PERSONAL PERSPECTIVES OF DEATH AND DYING

Death is a subject that many people have difficulty discussing or considering. It is an event that will impact every human's life, at least once. In this section we will discuss the following:

1. Define what it means to learn to die.
2. Discuss what it means to understand that dying is a natural, inevitable process.
3. Discuss the process of dying and death.
4. Discuss how the acceptance of death leads to an ability to live a more enriched life and die peacefully.

The ability to face the reality of death and its impact on our life and each other's lives and the ability to discuss our fears, anticipations, fantasies, etc., will better prepare us to fully live our lives. To fully live our lives we should "stop and smell the roses" and live our lives as if we knew we only had days to live; thus, learning how to die.

LEARNING TO DIE

Dying is the final stage of growth in the life cycle. To achieve the maximum experience from this stage, the dying person and his or her significant other(s) should be educated on the final stage of life. The educating of people about death, the processes of dying and grieving, and how to prepare to die, can ease the actual dying period by preparing all participants for the final moments of life.

Learning to die is directly associated with learning to live. By understanding the process of dying, accepting the physical finality of death and the development of an understanding of the psychological and spiritual self, individuals can free themselves from the fear of dying.

The fear of dying can be a possible underlying deterrent for being able to living a fruitful life. Through the attainment of an understanding and acceptance of death, life can be lived more fully and death can come more peacefully.

Many humans have difficulty conceptualizing the end of their own existence. The conscious mind has never knowingly experienced its own non-existence. It has no reference to what not being part of life is like. The human has no learned experiences of not being alive. It continuously attempts to rationalize, reason, or find purpose in death.

As the dying person nears death, the permanence of death becomes more real. He or she begins to realize that he or she is really going to cease to exist and that his or her memory in this life will not be under his or her control, but in the minds and memories of others. Proof of his or her existence, in this life, will be the memories that others have of him or her, the artifacts that he or she leaves, and the children that are a result of his or her life.

Guiding the dying person through what the dying process is going to be like, and helping him or her to prepare for the physiological and psychological effects of dying, can be beneficial for both

the dying person and the support personnel. This guidance is one of the areas where chaplains can be especially beneficial in the hospice setting, assisting a person with what to expect physically, cognitively, and emotionally as one dies.

Social opinions of death and the dying process can directly influence an individual's ability to accept the reality of death and the acceptance or rejection of the position that death is natural part of life and the final stage of physical growth. The following parable provides an illustration of a common human social response of not being comfortable to discuss the eternal presence of death in life.

"When the guests came in for dinner, there it was, quietly sitting and munching. The host, not wishing to upset his guests, made no reference to the horse; the guests, not wishing to upset the host, made no reference to the horse. Consequently, he or she ate his or her dinner in silence - so overwhelmed by the presence of the horse that he or she could neither carry on a conversation nor enjoy the dinner and so imbued with his or her notion of politeness that he or she dared not mention the horse. The horse, of course, was death."

Educating people about death prior to having to deal with it can ease the actual death experience and provide a calm, cohesive environment throughout this stage of life. It is an important life skill to learn to notice more and attempt to appreciate and experience everything throughout life instead of waiting until death is eminent.

During our lives we are taught about dying and the death process through the media of literature and dramatic interpretations, religion and philosophy, and by the experiences of others. The use of literature and audio-visual media, to depict an event that is final and permanent for an individual, can be helpful in developing the knowledge to prepare a person for his or her own death or the deaths of others.

It is also an opportunity for the individual to learn to appreciate and experience life vicariously. By seeing, hearing, or reading about the process of dying, a person can be detached from the process but can voyeuristically participate and learn about the process and act of dying.

Acceptance of death involves the growth of knowledge of self through psychological and spiritual development. Anxiety and fear of death can be alleviated by understanding death is the final stage of life and that it can be an enlightening experience for both the dying individual and his or her family and friends.

The acceptance of human mortality can be achieved by learning to prepare for death by taking care of personal business and gaining understanding that death and the dying process is a natural process that should not be feared.

UNDERSTANDING DEATH

Philosophical beliefs, religious beliefs, and cultural practices help to provide a person with a sense of understanding about death. Philosophical and religious beliefs provide a basis for the dying individual to psychologically and spiritually prepare for the inevitability of death. Cultural practices provide the foundation for the way individuals, who are touched by death, react and grieve.

Psychologically it is a lonely realization that our existence in this life and our continued memory is directly related to other people keeping our memories alive. Regardless of religious or philosophical beliefs, when we die we are no longer part of the reality of the life we know now, but only a memory in someone's mind.

As the dying person prepares to die, he or she begins to realize that he or she will only remain a part of this reality and the living world as long as his or her memory is kept alive in the memories of others. They realize that their existence will ultimately be forgotten and lost as those people that have memories of them die and that eventually, unless he or she has left a permanent imprint on this life's history, he or she will be forgotten and will permanently cease to exist. During life, the dying person keeps his or her own existence alive, in part, by the acts and events he or she is involved with and shares with others.

Each person has his or her own relationship with religion and his or her own perspective of death. It is through the belief in hope that most dying people deal with the loneliness and finality of death. Hope is the desire for some good, accompanied with at least a slight expectation of obtaining it, and the belief that good is obtainable. It is the confidence in a future event and/or the highest degree of well-founded expectation of good. It is in the hope of life after death that the individual is able to accept the end of this life and the beginning of another life.

Religious beliefs and social customs influence the dying person's attitude towards the transition from life into death and the grief processes of the family and friends that are left behind. Most religious teachings reflect upon preparing the individual to die and examining perspectives of life after death.

Much art, literature, and religion support the hope that humans have that there is life after death. There are numerous artistic renderings of scenes of life after death, literary interpretations of death and life after death and volumes of religious studies of life after death.

Each individual author's interpretation of death and life after death is shared through his or her art form. The artifacts of art, literature, and science provide monuments to individuals and society.

Human cultures accept and deal with the dying person and death differently. The individual who is dying also has a sense of loss for this life but, dependent on his or her cultural and religious foundation, a sense of hope and/or expectation for the future.

Universally, there is a sense of personal loss when a family member, friend, or associate dies. Grieving practices are personal and cultural activities. The differences in death depend upon the difference between disciplined and undisciplined living, between pure and impure mind or between “carefulness” and “carelessness”.

Practitioners of Hinduism and Buddhism believe that death should be considered an “ever present companion” in life. They feel the loss of their loved one, friend, or associate but they are confident in the dying person's afterlife. They believe that a person is continuously reborn to a new life until the person's spirit reaches the point of enlightenment and all knowing.

The Hindus and Buddhist believe there are differences in the quality of deaths just as there are differences in the quality of births and lives. Dying is taught as part of religion and culture so that when it is time to die, he or she will die peacefully.

Judeo-Christian culture and religion view death as a part of life, but as described in the parable of "The horse at the dining-room table", usually do not openly discuss death and dying. It is a subject that the general population places in its own time and place and do not make it an “ever present companion”.

Christians accept that there is an afterlife to their present existence. It is based on the belief that there is one lifetime and after death (Hebrews 9:27) the saved shall exist with God forever. The Bible teaches the individual how to live properly and to prepare to spend eternity with God.

Through understanding death from a philosophical, religious, and cultural perspective, the individual can psychologically begin to accept the inevitability and finality of death. Understanding and learning the process of dying, and what to expect as one dies, provides the individual with a level of knowledge that can alleviate some of the fear of the unknown.

THE DYING PROCESS

There are five general stages a person goes through when he or she learns that he or she is going to die. These stages are:

- denial & isolation,
- anger,
- bargaining,
- depression, and
- acceptance

The dying person does not necessarily go through all these stages in this order. Sometimes he or she may move from one stage to another and then back to a previous stage. Other times the dying person may move rapidly through the various stages and then settle into one stage for a significant period of time.

It is the role of the clergy and support people to help the dying person to reach the final stage of acceptance in order to achieve a peaceful transition from life into death.

There are also practical requirements that the dying person needs to attend to before he or she dies. The completion of these needs will give the person a feeling of some control of his or her life and a sense of accomplishment and completion. Some of these needs may be to complete any unfinished business, deal with any medical requirements to be comfortable, allocate personal time and energy, and make arrangements for after his or her death.

As death approaches, the dying individual may begin to lose strength, mental acuity, and the ability to care for him or herself. It is during this time that there is the greatest need for a support system. The dying person may become anxious and fearful if he or she is not prepared emotionally, psychologically, and spiritually to die.

By providing a calm, cohesive environment, during the final period of life and the knowledge of what to expect physically and psychologically, support personnel can aid the dying person to have a more peaceful, smooth, and fearless transition from this life into death. By providing a peaceful transition for the dying person, the family and friends that are associated with the dying process will have an easier grief process.

The process of dying is similar to the process of birthing. The dying person, very often, demonstrates similar breathing patterns as the expectant mother who is undergoing labor contractions. As death approaches, the dying person's breathing becomes more labored and the fear of the unknown becomes more prominent.

The expectant mother and her coach are taught breathing rhythms and mental exercises to ease the birthing process. Similar breathing and mental exercises can be taught to the dying person and his or her attendants to ease the dying process.

STAGES OF DEATH AND DYING

Dying is a process, the end point of which is death. In this sense dying is a terminal part of living. The coping responses during this particular segment of life are shaped by previous experiences with death, as well as by cultural attitudes and beliefs. Many dying people pass through these stages from the time they first become aware of their fatal prognosis to their actual death.

Elisabeth Kubler-Ross was a pioneer in the psychological field of death counseling. She helped start a movement that views a dying person as a thinking, feeling human being rather than a thing which must be dealt with; thus setting up the modern method of hospice care where emotions are cared for as well as physiological needs.

At the same time, while working with dying patients she analyzed what goes on in their minds. From her experience-oriented research, she found five specific emotional and mental stages that are consistent with almost all patients, all of which occur because they're emotionally beneficial in one way or another.

Usually the stages require a good amount of time to experience, as with a person diagnosed with a terminal illness. In sudden, unexpected deaths there simply isn't enough time to be emotionally and mentally affected in too many different ways.

These five stages don't usually follow any particular order, and each can be experienced more than one time.

State 1: Denial and Isolation

Stage 2: Anger

Stage 3: Bargaining

Stage 4: Depression

Stage 5: Acceptance

STAGE 1: DENIAL AND ISOLATION

Upon receiving the information that one will not be able to live much longer, one responds by thinking that it can't be true. The response comes from simple rationality. Such news often seems like a hasty conclusion, and like any other time when a rash statement is made, one says, "Now hang on a minute. Let's see if there's really any cause for alarm." Even though it's clear that there is no mistake, one still continues to make an effort to make sure it isn't a mistake.

In one case a woman insisted on going to many different doctors in the hopes that one of them would tell her what she wanted to hear – that she wasn't going to die. In most instances denial isn't of these proportions, but it does happen.

Denial also comes at varying times throughout a dying patient's final days; usually in milder, more subtle form. Sometimes one changes the subject when it's brought up, wanting to talk about something more cheerful and less negative. Isolation is very much linked to denial. By having less interaction with others, one escapes the possibility of talking about the subject. It's very rare, however, for denial and isolation to be severe. There are very few instances where a person makes a consistent, false reality all the way until the moment of death.

While both of these things sound like the "wrong way" to deal with death, they're an essential and natural way to relieve what can turn into constant negative emotion. The thought of one's own life ending soon is a thought that's very difficult to get out of one's mind. It's nearly impossible to see death, accept it, and look past it into the remaining time one has. So one must sometimes move the thought away, brush it aside, in order to look past it and live the remaining life.

STAGE 2: ANGER

"Why me?" is a question which is the product of resentment, rage, envy and anger. And like anger that arises in everyday situations, it can be transferred to people and situations that aren't related to what one is really angry at and which don't deserve such hostility. A patient might

complain about a health worker, maybe even directly to that person, or may be in a bad mood in general. Often what triggers anger is envy, observing something that one can no longer do because of new physical limitations, or something cherished that one will not be able to experience after one's life is over.

From such things, one can also have resentment towards their higher power, be it Buddha, God, etc, for making their life end. Also, the wish to convey that one is in fact still alive causes angry outbursts. Yelling and arguing are great ways to get attention, and sometimes one really wants others to be reminded that, while death is now a common topic of discussion, one isn't dead right now, not yet. Anger can be an assertion of life.

STAGE 3: BARGAINING

In the same way that a child, after being denied something, will volunteer to do a few household chores in the hopes that when posing the request again he will be granted his wish, a dying person will try to bargain with the higher power in which they believe.

This reaction comes from life experience. One can often make a deal in order to get what is wanted. This is a consistent strategy that's almost always worth trying during life, and when faced with something as strikingly negative as death, it's only natural to use a strategy which has succeeded so many times before.

One wants to postpone death as much as possible and promises might be made so that maybe they can live a little longer. Often this occurs in wanting to do a particular thing one last time, as in the opera singer who wishes to perform just once more, or the mother who wants to see her last son get married.

Bargaining also very often continues, having more promises to do good things in return for various experiences. This points to the idea that wanting particular things "one last time" is merely a reflection of the broader, deep desire to have one's time to live extended.

STAGE 4: DEPRESSION

This stage seems the most easy to understand – after all, who wouldn't be extremely sad when he is about to die? But depression for a dying person isn't as clear as it seems. There are two different kinds, with two different causes.

The first depression's source is found in frustration and complication. Having to think about finances, family's emotions, medications, examinations, and a world of other issues is overwhelming. Self-esteem is added into the mix when it's called into question by deteriorating physicality.

All this adds to the second stage of anger, but also often causes a melancholy sadness. The second depression that a dying person goes into is about grief. There's much emotional turmoil in

truly contemplating one's own death, and more significantly, the end of one's own life and all that is and used to be in it.

Just as when one cries and is filled with sorrow at a loved one's end, so does one who is dying themselves. And in the same manner, it acts as emotional cleansing, necessary to the path of eventual acceptance.

STAGE 5: ACCEPTANCE

A dying person, after enough time with the various stages in various orders, and even with various repetitions, comes to terms with their impending death. This is different than the acceptance of reality that occurs on the conscious, mental level of reason – that usually happens well before the final stage of acceptance.

It isn't the same as giving up, either; nor is it a time of joy. This is the acceptance of quiet expectation, when one is neither happy nor sad, but serene. One doesn't usually want to talk much or have things to do.

However, a good thing to have in this final stage is company. Someone who can sit silently by a bedside, maybe holding a hand, is the best person to be with a person in the calm of acceptance. A patient of Kubler-Ross described it as "the final rest before the long journey."

These stages are not all encompassing or prescriptive. Not everyone will reach these stages; perhaps only a few will reach acceptance. A patient may demonstrate aspects of all stages in one interview or may fluctuate between stages. Moreover, patients may exhibit other coping methods such as terror, humor, or compassion to offset each stage.

MANAGING DEATH ANXIETY

Human beings have a basic self-preservation drive. Combining this drive with the realization that death is inevitable creates in them a paralyzing terror of death. In other words, all human drama is, to a great extent, a story of how human beings cope with the terror of death, and how they overcome death anxiety through a great variety of conscious efforts and unconscious defense mechanisms.

Taking into consideration all these factors, it becomes necessary to help people manage death anxiety in such a way that facilitates growth. Following are some of the most commonly used techniques to deal with death anxiety.

DISPELLING THE FEAR OF DEATH

It is natural to feel fear of the unknown. In regard to death, this fear may be of what might happen during the process of dying, such as the pain of a terminal illness, nausea, vomiting, or even fearing abandonment by those around you.

The fear of death may also be perpetuated by the sadness of the family around the dying person, or the hopelessness of the doctor, or the nurses who may feel the failure to keep the person alive.

Death is not an enemy; it is a natural fact of life, a stage of our existence, and a transition or doorway between planes of reality. Death has its own harmony with nature just as a tree loses its leaves every fall. We don't feel that it is unjust or that the tree failed to stay fully alive when it goes dormant through the winter. It is natural.

Neither should doctors and nurses feel they have failed if a patient dies. Actually, it may be better to let a person take the opportunity to die peacefully rather than trying to force him or her to remain alive in a suffering body. In other words, it can be better to make peace with death than try to conquer it.

The process of dying can be rough, but it is temporary. Of course, it always may be a little sad to leave our home and loved ones, but if we are going to a bigger and more beautiful home, then what is there to be sorry about? It is joyful to be going to a better place. This sort of joy will also help divert our attention from any pain we may be feeling. Trust that God will take care of you. As you think about it, pray and ask for guidance. Let go of your expectations and let God show you the way.

We came into this temporary world through birth and must leave it through death. All of our possessions, relationships, even our talents and skills are temporary. So how can our body be anything more? Being afraid of death is like being afraid to give up an old and worn-out garment.

The mind is the root cause of fear and suffering. It projects its own level of reality out on the world and its own perception of things. When things are not the way we want them to be, or think they should be, our mind has difficulty accepting it and we suffer. We often get angry, anxious, confused, or fall into fear.

LIVE WHEN YOU ARE DYING

Once we learn that we are dying, human beings have a difficult and contradictory challenge; we are dying, we know we are dying, yet we want to live. There are several things that must be done while in the process of dying.

ACKNOWLEDGE YOU ARE DYING

Acknowledging you are dying is the first step to living the rest of your life. If the onset of your illness was sudden or unexpected, you will likely feel shock and numbness at first. This is a natural and necessary response to painful news. You can only cope with this new reality in doses. You will first come to understand it with your head, and only over time will you come to understand it with your heart.

To acknowledge you are dying is to let go of the future. It is to live only in the present. There is no easy way to do this, and you will probably struggle with this task every day until you die. Know that if you work at acknowledging the reality of your coming death, however, instead of denying it, you will open your heart and mind to the possibility of a new, rich way of living.

QUESTION THE MEANING OF LIFE

Discovering that you are dying naturally makes you take inventory of your life. You have a right to have questions, fears and hopes. Illness establishes new directions and often causes some questioning of old directions. New thoughts, feelings and action patterns will emerge.

The unknown invites you to question and search for the meaning of your life, in the past, present and future.

ACCEPT YOUR RESPONSE TO THE ILLNESS

Each person responds to news of terminal illness in his or her own unique way. You, too, will have your own response, be it fear, excitement, anger, loss, grief, denial, hope or any combination of emotions.

Becoming aware of how you respond right now is to discover how you will live with your terminal illness. Don't let others prescribe how you feel; find people who encourage you to teach them how you feel. After all, there is no right or wrong way for you to think and feel.

RESPECT YOUR OWN NEED FOR TALK, FOR SILENCE

You may find that you don't want to talk about your illness at all. Or you may find that you want to talk about it with some people, but not with others. In general, open and honest communication is a good idea. When you make your thoughts and feelings known, you are more likely to receive the kind of care and companionship you feel will be most helpful to you. But if you don't want to talk about your illness, don't force yourself. Perhaps you will be able to open up more later on, after you have lived with the reality of your illness for a time.

TELLING YOUR FAMILY AND FRIENDS YOU ARE DYING

Your family and closest friends deserve to know that you are dying. Tell them when you feel able to. If you simply cannot bring yourself to tell them, find a compassionate person with whom you can entrust this important task.

Be aware that everyone will react differently to your news, just as each terminally ill person reacts differently to his or her own illness. Many will be shocked. Many will cry. Some will refuse to believe it. Some will spring into helpful action by running errands for you, offering to clean your house, etc.

Many will not know how to respond. Because they don't know what to say or do, or because your illness may arouse their own fears of mortality, they may even avoid you altogether. Know that their apparent abandonment does not mean they don't love you.

Even children deserve to be told. As with all people, children can cope with what they know. They cannot cope with what they don't know. Be honest with them as you explain the situation in language they will understand. Don't over explain, but do answer any questions they may have.

BE AN ACTIVE PARTICIPANT IN YOUR MEDICAL CARE

Many people are taught as "patients" to be passive recipients of the care provided by medical experts. But don't forget this – this is your body; your life. Don't fail to ask questions that are important to your emotional and physical well-being out of fear that you will be "taking up someone's time."

LEARN ABOUT YOUR ILLNESS

Visit your local library and consult the medical reference books. Request information from educational associations, such as the National Cancer Institute or the American Heart Association, or check online support groups. Ask your doctor, nurses and other caregivers whenever you have a question.

If you educate yourself about the illness and its probable course, you will better understand what is happening to you. You will be better equipped to advocate for personalized, compassionate care. You may not be in control of your illness, but you can and should be in control of your care.

BE TOLERANT OF YOUR PHYSICAL AND EMOTIONAL LIMITS

Your illness will almost surely leave you feeling fatigued. Your ability to think clearly and make decisions may be impaired and your low energy level may naturally slow you down. Respect

what your body and mind are telling you. Nurture yourself. Get enough rest. Eat balanced meals. Lighten your schedule as much as possible.

SAY GOOD-BYE

Knowing you will die offers you a special privilege: saying good-bye to those you love. When you feel you are ready, consider how you will say good-bye. You might set aside a time to talk to each person individually. Or, if you are physically up for it, you might have a gathering for friends and family. Other ways of saying good-bye include writing letters, creating videotapes and passing along keepsakes. Your survivors will cherish forever your heartfelt good-byes.

FIND HOPE

When we are seriously ill, we tend to get caught up in statistics and averages; How soon will the illness progress? How long do I have left? These can be helpful to know, but they don't always provide spiritual and emotional comfort.

Even if you are certain to die from your illness, you can find hope in your tomorrows, your next visit from someone loved, and your spirituality. At bottom, hope means finding meaning in life, whether that life will last five more days, five more months or five more years.

EMBRACE YOUR SPIRITUALITY

If faith is part of your life, express it in ways that seem appropriate to you. You may find comfort and hope in reading spiritual texts, attending religious services or praying. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because of your illness, realize that this is a normal and natural response. Find someone to talk to who won't be critical of whatever thoughts and feelings you need to explore.

REACH OUT FOR SUPPORT

Many of us grew up believing, "Do it on your own so you don't have to depend on anyone else." But confronting a terminal illness cannot and should not be done alone. As difficult as it may be for you, you must reach out to your fellow human beings.

Most of us know whom we feel comfortable turning to when we are under stress. Whom do you turn to? Give yourself permission to reach out for prayers, support and practical assistance.

Hospices are an indispensable resource. They are well staffed and trained to help both the dying person and the dying person's family. Their mission is to help the dying die with comfort, dignity, and love, and to help survivors cope both before and after death. They often offer support groups for people with life threatening illness. You might also consider seeing a

counselor one-on-one. Whatever you do, don't isolate yourself and withdraw from people who love you.

ADVANCE DIRECTIVES

“Advance directive” is a general term that refers to your oral and written instructions about your future medical care, in the event that you become unable to speak for yourself.

Each state regulates the use of advance directives differently. There are two types of advance directives: a living will and a medical power of attorney.

WHAT IS A LIVING WILL?

A living will is a written, legal document which spells out the types of medical treatments and life-sustaining measures you do and don't want, such as mechanical breathing (respiration and ventilation), tube feeding, and resuscitation, should you become unable to communicate at the end of life. In some states the living will may be known by a different name, such as health care declaration or health care directive.

Your state law may define when the living will goes into effect, and may limit the treatments to which the living will applies. Your right to accept or refuse treatment is protected by constitutional and common law.

WHAT IS A MEDICAL POWER OF ATTORNEY?

A medical power of attorney is a document that enables you to appoint someone you trust to make decisions about your medical care if you cannot make those decisions yourself. This type of advance directive may also be called a “health care proxy” or “appointment of a health care agent.” The person you appoint may be called your health care agent, surrogate, attorney-in-fact, or proxy.

These forms allow your health care agent or proxy to use a living will as a guide, but interpret your wishes when unexpected developments aren't specifically addressed by your living will. The medical POA document is different from the power of attorney form that authorizes someone to make financial transactions for you. If you don't appoint a medical POA, the decisions about your care generally defaults to your spouse. If you aren't legally married, decisions fall to your adult children or your parents.

In many states, the person you appoint through a medical power of attorney is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

WHAT IS A DNR?

This is a request to not have cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing. A DNR order can be put in your medical chart by your doctor.

WHY DO I NEED AN ADVANCE DIRECTIVE?

Advance directives give you a voice in decisions about your medical care when you are unconscious or too ill to communicate. As long as you are able to express your own decisions, your advance directives will not be used and you can accept or refuse any medical treatment. But if you become seriously ill, you may lose the ability to participate in decisions about your own treatment.

Once you've filled out the forms, give copies to your doctor, the person you've chosen as your medical POA, and other friends and family members. Your instinct might be to put your advance directives away somewhere safe, like a safe deposit box, but that will only make it difficult for your loved ones to find the forms when they need them.

Both federal and state laws govern the use of advance directives. The federal law, the Self-determination Act, requires health care facilities that receive Medicaid and Medicare funds to inform patients of their rights to execute advance directives. All 50 states and the District of Columbia have laws recognizing the use of advance directives.

A doctor can give you the proper forms or state-specific forms are available from a variety of Web sites.

DEATH WITH DIGNITY

What is death with dignity? Is it a new-found right based on the autonomy of self-determination and total freedom? Saints and martyrs for the faith are not known in a secular sense for their dignified deaths. Did Jesus die a dignified death? Death with dignity is somewhat oxymoronic.

Death is ugly, and in an earthly way it cannot be good. It is the price we pay for the sin in the Garden of Eden. Dignity in the face of death cannot be given from the outside; it requires the dignity of the soul in the human being who faces it.

Dying people are all too easily reduced to “thing-hood” by those who cannot bear to deal with the suffering and disability of the ones they love. Detachment is an understandable defense; but this withdrawal of contact, affection, and care is probably the greatest single cause of the dehumanization of dying.

If there can be any dignity in the dying, it must be the continued treatment, until the very end, of the person as someone made in the “image and likeness of God.”

Theologian William May notes that the bodily life of a human person, however heavily burdened it may be, is still a person's life, his very being. It should also be clear that any concept of “death with dignity” should more appropriately be thought of as living with dignity in the face of death.

A dignified death has nothing to do with the pulling of plugs or the administration of poisons; to think this way, as so often is the case in our secular society, renders death even more undignified. If it is really death with dignity that we are after, we must think in human terms and not in technical terms. If we are talking about dignity at the end of life, we are talking about helping one die and not making one die.

SANCTITY OF LIFE

God said in the very beginning, “Let us make man in our image.” (Gen. 1:26, NAV). Man is like God in that he has a free will and an intellect. Man is willed by his Creator to be ruler over all the other creatures. He was created to exercise dominion over the world as the Creator has dominion over the universe. “From man in regard to his fellow man I will demand an accounting for human life.” (Gen. 9:5).

The divine commandment is given, “You shall not kill.” (Exod. 20:13). This commandment is found in the Decalogue, the heart of the covenant of the chosen people; it was already contained in the original covenant between God and humanity after the purifying punishment of the Flood, caused by the spread of sin and violence.

What is meant by the sanctity of life? It would appear in the strictest sense to mean that life is something holy, transcendent, and set apart by God himself.

Life is something that is not easily fathomable. In more modest terms, it could be said that, since life is sacred, it should not be violated, opposed, or destroyed; more positively, it should be protected, defended, and preserved.

Sacredness inheres in life itself, and that life, by its very being, calls forth an appropriate human response, whether it is veneration or restraint. To say that sacredness is something that can be conferred or ascribed – or removed – solely by human argument or decision is to focus on some self-centered concept. This is truly egoism.

If one is to believe in the sanctity of life, one cannot believe in “mercy killing” or since this would be a violation against God himself, by way of killing His likeness. To judge that a person's life no longer has any value, that it is worthless, is to judge that a person no longer has any value. Does a person with senile dementia or an infant with a severe congenital anomaly no longer have any value?

The advocates of euthanasia regard human persons as consciously expressing subjects, free to do as they choose, and bodily life as merely an instrumental good, a good for persons who are consciously aware of their being. If life becomes burdensome, it is something one should be free to put aside. As its proponents so perceptively say, “I belong to myself, and I can set conditions

on which I will consent to go on living.” Life is regarded as a good or bad hotel, which must be in decent condition if I am to stay in it.

What is the motivating force of total autonomy, an autonomy that implies a total freedom, even a freedom from virtue and truth? It seems to be a “freedom of indifference,” as opposed to “freedom for excellence.”

Death is inversely proportional to life satisfaction. When an individual is living authentically, anxiety and fear of death decrease. The central objective of existential psychotherapy is to enable the person to live authentically, actively observed and involved with other people and things, while appreciating and accepting his nature as being the world (Encyclopedia of Psychotherapy, 2002).

Human beings are in a presumably unique position as compared to other species, given that they are forward-looking and can anticipate some aspects of the future. Ultimately, the future brings death for all.

Recognition of death plays a significant role in psychotherapy, for it can be the factor that helps us transform a stale mode of living into a more authentic one. Confronting this realization produces anxiety. People can face pain, guilt, despair and death in their confrontation, challenge their despair and thus triumph.

A distinguishing human character is the ability to grasp the reality of the future and inevitability of death. It is necessary to think about death if we are to think significantly about life. If we defend ourselves against the reality of our eventual death, life becomes insipid and meaningless. But if we realize that we are mortal, we know that we do not have an eternity to complete our projects and that each present moment is crucial. In this way our awareness of death is the source of zest for life and creativity.

DEATH ANXIETY

The relief of suffering is one of the central goals of palliative care in terminal illnesses. Suffering is frequently associated with the experience of aversive physical symptoms (e.g., pain); however, many patients suffer even in the absence of such symptoms. Secondly, suffering due to advanced disease does not appear to be limited to the affected.

Family members also suffer, which may, in turn, exacerbate the patient’s suffering. According to psychosocial perspective, suffering is best viewed as a subjective phenomenon that can be influenced by biological, psychological, and social processes.

The potential sources of suffering in terminal illnesses can extend beyond physical symptoms to include psychological and psychiatric complications (e.g., anxiety, depression, and cognitive disorders) and existential distress emanating from past, present, and future concerns.

Relief of these sources of suffering can be achieved through a multidisciplinary approach to patient care in which experts in mental health and pastoral care contribute to the treatment effort. Addressing the psychosocial aspects as well as the medical aspects of palliative care can further reduce the suffering experienced by patients with terminal illnesses.

There are seven essential features in the management of the dying:

Concern: Empathy, compassion, and involvement are essential.

Competence: Skill and knowledge can be as reassuring as warmth and concern. Patients benefit immeasurably from the reassurance that their providers will not allow them to live or die in pain.

Communication: Allow patients to speak their minds and get to know them.

Children: If children want to visit the dying, it is generally advisable; they bring consolation to dying patients.

Cohesion: Family cohesion reassures both the patient and family. The clinician who gets to know the family maximizes support and is prepared to help the family through bereavement.

Cheerfulness: A gentle, appropriate sense of humor can be palliative; a somber or anxious demeanor should be avoided.

Consistency: Continuing, persistent attention is highly valued by patients who often fear that they are a burden and will be abandoned; consistent physician / chaplain involvement mitigates these fears.

MEANING MANAGEMENT MODEL

How we view death and how we cope with death anxiety can profoundly affect every aspect of our lives – either positively or negatively. This model (Wong, 2002) proposes that meaning management is more adaptive than terror management in dealing with death anxiety. Death is the only certainty in life. All living organisms die; there is no exception.

However, human beings alone are burdened with the cognitive capacity to be aware of their own inevitable mortality and to fear what may come afterwards. Furthermore, their capacity to reflect on the meaning of life and death creates additional existential anxiety.

According to Goodman (1981), “The existential fear of death, the fear of not existing, is the hardest to conquer. Most defensive structures, such as the denial of reality, rationalization, insulation erected to ward off religiously conditioned separation-abandonment fears, do not lend themselves readily as protective barriers against the existential fear of death”.

To cope with fear of non-being, people resort to various kinds of symbolic immortality by assuming that one can live forever through progeny (Biological), believing in an afterlife and that the soul never dies (Religious and spiritual), living through one's works (Creative), through the survival of nature itself (Natural) and through identification with an institution or tradition (Cultural).

Acceptance of death involves a willingness to let go and detach oneself from events and things which one used to value. The meaning management model emphasizes that human beings are born with the innate need for meaning, but it may lie dormant because of our preoccupation with the business of living; and death and suffering awaken in us the urgent need to search for meaning and purpose for life and death. We can discover and create meaning in every situation, even in the face of death.

Meaning management helps deepen one's faith and spirituality and also enables one to achieve a better understanding of the meaning and purpose of life. It helps construct a useful psychological and spiritual model that offers the best protection against the fear of death and dying. It motivates us to embrace life – to engage in the business of living, regardless of our physical condition and present circumstances.

It is not just rationalization or cognitive reframing, but a reconstruction and transformation of values, beliefs and meaning systems. It emphasizes that the way we live foreshadows the way we die. By accepting death and understanding its full meaning, we acquire wisdom. By accepting death through faith, we find courage and an undying hope.

PHYSICAL SYMPTOMS OF DYING

It is important for the hospice chaplain to know when the end is near and why certain procedures or actions are taking place. The chaplain will be there for the dying person and the family and if he/she is aware when the end is near or why something is being done, the chaplain may be able to explain to the family what is occurring and so the chaplain will be better prepared for expected death, not for himself but for the family.

An understanding of the physical changes that occur during illness and death, as well as issues of pain management, is critical for any caregiver offering support to dying persons and their families. Generally, patients portray specific physical symptoms that indicate they are approaching death.

Many of us who are involved in the care for someone have never witnessed someone dying. It is hard, both physically and emotionally, to know and accept that someone we are caring for is near death. But if caregivers are aware of these symptoms, then they will be better prepared to give their loved one the best care possible in the final days. Knowing the signs of death will also help caregivers to prepare the rest of the family.

Whether you are the caregiver, or anyone who is involved in the life of the person dying, we hope that by knowing some physical aspects of the death process, you will be able to understand what is happening with your loved one, and what you can do to help.

NUTRITION AND HYDRATION

The notion of caregivers not providing normal amounts of food or water runs counter to all we have been taught in medical training, much less what we hold to be necessary in everyday society. Yet because of the advances of science we are now able to prolong the lives of persons who would not survive without external support, mechanical devices, or, at times, intravenous or central line nutrition and water.

Physicians and bio-ethicists who work with dying persons have grappled with the dilemma of what is reasonable care for a dying person. There comes a time in some cases where even nutrition and hydration are considered extraordinary means of prolonging life, and such ordinary nutrients are discontinued.

This is never done without great and careful consideration. The decision to withhold food and/or fluid is made only when it is apparent to the caregivers and family that further prolongation of life would only extend discomfort. This decision should be made with the patient, if able to understand, and the family being fully informed of all considerations. Ideally, the family is then involved in making the decision to withhold food and fluids.

For persons in the final phase of illness, the withholding of food and fluids is not painful. To the contrary: the administration of food and fluids to dying persons can extend their general discomfort and frustrate their desire to just let go and allow nature to take its course.

In cases where people cannot swallow, it is standard care to apply moisture in some form to the lips and mouth regardless of whether or not the patient is ever able to swallow again. This is basic oral hygiene. This is comfort care. Applying moisture should be done even if a person with advanced illness is able to take oral fluids.

In instances when it is determined that the person is dying and it is further determined that hydration would only prolong the discomfort, dehydration is not a painful process. There is a side effect of starvation and dehydration in which one's metabolism changes and the resulting elevated level of ketones produces a mild sense of euphoria, so that hunger and thirst are not the problem we would imagine.

It is this sort of information that underlies the bio-ethical support for withholding nutrition in those persons with advanced illness whose greatly impaired quality of life would not be improved, but only prolonged, by supplemental (intravenous or cut-down) methods of delivering nutrition and hydration.

STATES OF CONSCIOUSNESS AS DEATH APPROACHES

The individual's state of consciousness may fluctuate as the changes associated with dying affect the central nervous system. They may go in and out of a lower level of consciousness. It is not unusual for patients to experience sensory changes. Some important definitions:

- **Illusions** – misperceptions of ordinary sensations.
- **Delusions** – misconceptions of reality. Two major types:
 - Grandeur – exalted sense of self
 - Persecution – fear that others are trying to inflict injury
- **Hallucinations:** three major types of hallucinations:
 - Auditory – hearing things (usually voices) not present
 - Visual – seeing things not present
 - Tactile – feeling things not present

Persons in a coma may still hear what is said even when they no longer seem to respond to verbal or even painful stimuli. Caregivers, family, clergy and physicians should always act as if the dying patient is aware of what is going on and is able to hear and understand voices.

The pulse may change in rate and regularity. It may slow and become irregular. The blood pressure may fall. The extremities usually become cooler. Breathing may become labored. Fluid may accumulate in the lungs causing “rattles.” The liquid sounds sometimes heard at the end of life are not an indication of pain or suffering.

The secretions that cause these sounds can be dried up with a small injection of a specific medication (atropine) or the oral administration of a small amount of a common eye drop solution usually prescribed to reduce the amount of tears. Also running a vaporizer in the patient's room can ease breathing when lung secretions are dry.

Periods of breathing may alternate with periods of no respiration; this is known as “Cheyne-Stokes” respiration. The skin may become pale, cool and moist. The skin of the feet and hands may become cooler than the skin of the trunk. Later, the skin may appear grayish or even a pale blue color.

MYTHS ABOUT DYING

Many pervasive cultural misconceptions about dying exist that can interfere with people receiving the best possible care at the end of life. Debunking these myths and understanding the realities can allow you to better support the dying person and loved ones.

“Death is too frightening to talk about.” “It's not normal to talk about death.”

Death has been remote, hidden away in the back rooms of hospitals. Remember; everything that lives, dies. Death can be a positive experience, not only for the dying person but also for family and friends.

In order for it to be a positive experience, we must recognize the needs of dying people as well as the needs of their caregivers. The family must be aware that dying people have special needs that can be met.

“People die as they have lived.”

This is generally true, yet it is also possible for people to change. If people receive excellent care during their last illness there can be great opportunity for reminiscence, for forgiveness of past difficulties, and for spiritual growth. This is only possible if there is good communication and openness among patients, caregivers and family.

“Dying is always painful.”

This is one of the most common misconceptions about dying. Pain can be relieved safely without any danger of death or addiction. Hospice caregivers and most doctors are familiar with the proper use of analgesic drugs. When given in the correct dose at the right time, pain can be relieved without sedating the patient.

When pain is relieved, patients can experience a good quality of life until the time that death occurs. Good pain management does not shorten the course of life. On the contrary, patients who receive excellent pain management tend to live longer than expected.

“While dying, people see a white light, a tunnel, etc.”

In general, this is not true. As people die there are physical and chemical changes in the brain that result in a gradual loss of consciousness. Some people experience what are known as delusions, illusions, or hallucinations, similar to dreaming while still awake.

Some persons relate seeing relatives who have previously died. In almost all instances, these last visions are usually pleasant and offer comfort to the dying person, especially regarding the prospect of reuniting with deceased loved ones.

GOALS OF CARE

In most cases, patients with advanced diseases experience suffering from multiple origins. They have physical problems such as pain, nausea, and shortness of breath, and they have psychological problems such as anxiety and depression.

These problems can be handled by a variety of medical interventions and psychotherapy. But when the patient is dying, they have existential problems as well, which underlie the physical and psychological, and in many ways are more difficult to address. Moreover, all these elements extend to the family of the patient in one way or another.

The list below has been compiled by hospice physicians, nurses, social workers and aides over 25 years of speaking directly to the dying. This list is not presumed to be complete, and it does not deal with individual variations, but it will help keep you focused on what should be the central point of care giving; addressing the dying person's needs.

NEEDS OF DYING PEOPLE

- Assurance that they will be cared for, that they will not be abandoned.
- Assistance in developing and finalizing documents pertaining to terminal care.
- Information that will be accurate, timely, and reliable.
- Communication that is timely, honest, and open with family, friends, and caregivers; people who will listen.
- Opportunity to discuss their impending death (if desired) with selected family and caregivers.
- Excellence in the delivery of physical care, comfort, privacy, intimacy, sleep, and rest.
- Management of pain and other symptoms that is responsive to changing conditions.
- Permission to express feelings, both positive and negative; to say “thank you, I love you, I forgive you,” as well as to express dissatisfaction, anger, and resentment.
- Opportunity to explore their finiteness and the spiritual dimensions of life.
- Opportunity to discuss preferences about funeral arrangements as well as the impact of dying on survivors.
- Time to reflect on the implications of the diagnosis and prognosis, to identify and attend to thoughts, feelings and needs.
- Time to tell their story, to re-affirm their identity and value their life.
- Time to reflect on and to grieve prior as well as current losses.
- Time with selected family and friends.
- Time to attend to unfinished personal business.
- Time to plan for distribution of assets and to address their financial responsibilities.

Once the needs of dying persons are understood and accepted, we are then able to refocus the goals of care. Instead of hoping for a cure, the dying person has a right to hope for a comfortable death, free of pain and discomfort.

The dying person can retain the hope of finding or re-finding the value of his or her life; of resolving what was previously not able to be resolved; discovering or re-discovering spirituality. The dying person may renew a quest for answers to great existential questions. It is not unusual for the dying person to find deep reservoirs of faith that were never suspected before. There is much that a dying person can hope for.

LIFE SUPPORT MEASURES

The following discussion of life-support measures is included here because an understanding of the effect of these interventions is necessary to set goals of care. Families may wish for comfort care but due to misinformation may give confusing instructions on life-support measures.

Artificial nutrition and hydration

Artificial nutrition and hydration (or tube feeding) supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine, or a vein. Artificial nutrition and hydration can save lives when used until the body heals.

Long-term artificial nutrition and hydration may be given to people with serious intestinal disorders that impair their ability to digest food, thereby helping them to enjoy a quality of life that is important to them. But long-term use of tube feeding frequently is given to people with irreversible and end-stage conditions.

Often the treatment will not reverse the course of the disease itself or improve the quality of life. Some health care facilities and physicians may not agree with stopping or withdrawing tube feeding. Therefore, this issue should be explored with family and physicians, and the individual's wishes should be clearly stated about artificial nutrition and hydration in the advance directives.

Cardiopulmonary resuscitation

Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone's heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart's function and cause the blood to circulate.

Electric shock and drugs are also used frequently to stimulate the heart. When used quickly in response to a sudden event like a heart attack or drowning, CPR can be life saving, but the success rate is extremely low for people who are at the end of a terminal disease process.

PAIN MANAGEMENT

Patients in pain may develop behaviors that are misinterpreted as drug seeking behaviors. They request increased doses or take more medicine than prescribed. Studies of cancer s have linked these behaviors to inadequate dosages of pain medications. Once pain is properly managed, these behaviors stop.

Morphine and narcotic analgesics have different side effects when administered orally than through an IV. Since you are likely to see both cases, we will discuss both.

Sedation: When properly used, the onset of orally administered opioid analgesics brings with it a normal period of sleep. Narcotics exert a calming, relaxing effect through direct sedative action on the brain as well as through relief of pain.

Patients often sleep after receiving pain relief because they have been sleep-deprived for days or weeks with recurrent episodes of pain. Such sleeping patients are easily roused by calling their name or touching them. Tolerance develops rapidly to this initial, sedative side-effect, and patients on even large doses of narcotic analgesics can be clear-headed, aware of all that is happening, and be involved in decisions affecting their care.

Intentionally sedated patients (from heavy IV doses) cannot be easily roused. To get such sedated persons back to clear consciousness, it may be necessary to administer one of the opioid antagonists that block the presence of opioids in opioid receptors. Resorting to this is rare.

Respiratory Suppression: Another side effect of high-dose IV opioids is the risk of respiratory suppression. This does not occur with gradual increases in the oral dose of opioid analgesics. Too much respiratory depression can occur in persons who are new to opioids and have not developed the tolerance to the respiratory suppression side-effect of opioids that usually develops after several days of regular opioid use.

Slowed Respiration: Because the respiratory rate of patients in pain is usually higher than normal, a slower rate of breathing is rarely a problem. Patients receiving narcotic analgesics usually breathe less frequently, but take deeper breaths. Like the sedative side effect, slowed respiratory rate is a transient side effect and, if present, fades after several days.

Constipation: A major side effect of narcotic analgesics is constipation; which must be managed not only with stool softeners, but with laxatives like senna derivatives, that stimulate bowel activity. Laxatives must be provided on a regular basis as long as patients are receiving narcotic analgesics.

In summary, there is almost always something that can be done to relieve severe, chronic pain in advanced illness. Hospice work has taught us that chronic, severe pain is a complex psycho-physiological process that is best treated by a number of approaches that includes narcotic analgesics, psycho-social support and the use of a wide variety of therapies ranging from massage to nerve block.

COMMON MYTHS ABOUT PAIN

Myth: *“Dying is always painful.”*

Many people die without experiencing pain. If pain does occur, it can be relieved safely and rapidly.

Myth: *“There are some kinds of pain that can’t be relieved.”*

There are some types of pain that require “multi-modality” (combined approaches) pain relief. Recent advances in analgesia assure that all pain can be relieved by using commonly available medications and/or a combination of approaches that may include chemotherapy, radiation therapy, nerve block, physical therapies and whatever else is appropriate.

Myth: *“Pain medications always cause heavy sedation.”*

Most people with severe, chronic pain have been unable to sleep because of their pain. The opioid analgesics (morphine, codeine, et al.) produce initial sedation (usually about 24 hours) that allows patients to catch up on their lost sleep. With continuing doses of medication they are able to carry on normal mental activities. Sedation often occurs because of other drugs, such as anti-anxiety agents and tranquilizers that have been prescribed for other reasons.

Myth: *“It is best to save the stronger pain relievers until the very end.”*

If pain is not relieved by the lesser strength analgesics (aspirin, NSAIDs, codeine, hydrocodone, etc.) then it is best to change to a stronger analgesic to bring the pain under continuing (24 hour) control. Pain that is only partially or occasionally controlled tends to increase in severity. This leads to two mistaken assumptions: The patient mistakenly fears that the pain is so severe that it can never be controlled; the doctor mistakenly believes that the patient is becoming addicted or is developing tolerance to the analgesic medication. In most cases, an adequate dose of a stronger analgesic (e.g., morphine) prescribed on a regular basis usually brings the pain under control.

Myth: *“Patient’s often develop tolerance to pain medications like morphine.”*

When morphine and other opioid analgesics are prescribed for the management of pain, the dose is sometimes raised to be sure that pain is well-controlled 24 hours a day, seven days a week. Opioids given to relieve pain generally do not lead to the development of tolerance. As a disease, like cancer, progresses, more opioid may be needed to control the pain on a continuing basis.

Myth: *“Once you start pain medicines, you always have to increase the dose.”*

In fact, the converse is true. Once pain is under control and the dose of opioid held at a steady level for several days, the dose of opioid analgesic can be lowered without the pain recurring. Levels of opioid can be raised safely as needed to control increasing pain. Also, the dose can be lowered gradually if pain has been controlled on the same dose for several days. This change in dose to meet patient’s needs is known as “titration.” The fact that the dose of opioid can be lowered once pain is controlled is one of the paradoxes of treating severe, chronic pain.

Myth: *“To get good pain relief, you have to take injections.”*

Until the mid-1970s it was believed that morphine was not an effective analgesic when administered by mouth, so it was universally administered by injection. We now know that morphine is effective when given by mouth or by suppository.

Patients generally do not like injections, as they are painful in themselves. There are several excellent long-acting opioid analgesic preparations. Morphine and related opioids are available that control pain for 12 hours when used on a regular basis twice daily. Other long acting opioid preparations available for trans-dermal (through the skin) delivery are available with a 72-hour (3-day) period of action.

Myth: *“Pain medications always lead to addiction.”*

When prescribed on a regular basis in a dose sufficient to relieve pain, there is no empirically based evidence that opioids lead to addiction.

Myth: *“Withdrawal is always a problem with pain medications.”*

When prescribed for managing severe chronic pain, there is no problem discontinuing the dose once pain is controlled. Withdrawal from the opioid analgesics is not a life-threatening condition as is withdrawal from a number of other commonly prescribed medications, such as barbiturates.

The symptoms of withdrawal from opioids are generally mild and fairly easy to manage with commonly available medications. Many patients who receive opioids for severe pain have had their dose adjusted down without experiencing any withdrawal symptoms.

Myth: *“Enduring pain and suffering can enhance one’s character.”*

This myth developed in the years before we learned to provide excellent pain management, but is not appropriate today. Suffering does not enhance character or earn people a higher place in the life hereafter; it merely brings about a miserable life, a horrible death and needless anguish in all who see helpless dying people suffer.

Myth: *“Once you start taking morphine, the end is always near.”*

Morphine does not initiate the final phase of life or lead directly to death. Morphine provides not only relief of severe, chronic pain; it also provides a sense of comfort. It makes breathing easier. It lets the patient relax and sleep. It does not cloud consciousness or lead to death. Morphine does not kill.

Myth: *“Pain is a solitary phenomenon.”*

Severe chronic pain never occurs alone, but is usually accompanied by a number of other symptoms including (but not limited to) anxiety, depression, fearfulness, insomnia, anorexia (loss of appetite), withdrawal and thoughts of suicide. All of these symptoms are compounded with memories of pain already experienced, currently perceived pain, and anticipation of more pain yet to come. Unmanaged (or inadequately managed) severe, chronic pain is a complex problem that needlessly aggravates the symptoms of the underlying disease.

Myth: *“Heroin is needed to provide excellent pain control.”*

Heroin is a derivative of morphine that is more soluble in water than morphine and therefore passes from the blood to the brain more rapidly, thus affording the ‘rush’ or ‘high’ desired by intravenous drug abusers. Morphine has a longer period of action. It can be safely taken by mouth. New preparations for sustained release make it possible to obtain excellent relief when taken by mouth only twice daily.

Myth: *“People have to be in a hospital to receive effective pain management.”*

It is easier to provide safe, effective relief of severe chronic pain at home than it is in the average hospital. There are fewer medication errors when there is only one patient to receive medications and no other emergencies to interrupt the care.

NEAR DEATH

Each person and every death is unique, but there are some common things that accompany the process of dying. These changes are natural and can happen over months, days or hours.

- Withdrawal from friends and family
- Loss of interest in favorite TV shows, friends, even their pets
- Desire to reminisce about joys and sorrows
- Sleep a lot more, or sleep for a few hours at a time, day and night
- Appear drowsy and confused
- Worries or concerns may keep them up at night
- Prefer to be alone
- Increasing weakness and fatigue
- Will have good and bad days
- Require help with personal care
- No appetite

As the body naturally shuts down, your loved one will need and want less food. Offer small amounts of the food they enjoy. Since chewing takes energy, they may prefer milkshakes, ice cream or pudding. Offer sips of fluids as long as they can comfortably swallow. Use a flexible straw if they have difficulty sitting up. When a person can no longer swallow, offer bits of ice chips. Keep lips moist with lip balm and their mouth clean and moist with a soft damp cloth.

NEAR DEATH AWARENESS

Near the end of life, people often have episodes of confusion, or waking dreams. Sometimes they may report seeing or speaking with loved ones who have died. They may talk about going on a trip, seeing lights, butterflies or other symbols of a reality we cannot see.

As long as these things are not disturbing to the patient, respond by asking them to tell you more. Let them share these visions and dreams with you and try not to talk them out of what they believe they see.

The patient may sleep more and, over time, seem unable to respond at all. Continue to talk to them, even if unconscious, as they may hear you. Talk to them, share your favorite memories, pray or play favorite music.

You will notice a decrease in urination, it may be dark and smell strong and the patient might have bowel changes. You can continue to provide clean dry bedding and provide gentle personal care; the care team will help you manage this care.

Touch lets the patient know you are there, as long as it doesn't cause pain.

Breathing patterns often change, becoming slower or faster, in cycles. In most cases this is unnoticed by the person who is dying, but let the care team know if you notice these changes.

As blood flow slows, some parts of the body may discolor and feel cool. This is not painful or uncomfortable; simply keep the patient covered with a light blanket.

WHAT HAPPENS WHEN DEATH COMES

ONE TO THREE MONTHS PRIOR TO DEATH

As one begins to accept their mortality and realizes that death is approaching, they may begin to withdraw from their surroundings. They are beginning the process of separating from the world and those in it. They may decline visits from friends, neighbors, and even family members. They are beginning to contemplate their life and revisit old memories. They may be evaluating how they lived their life and sorting through any regrets.

Food becomes less appealing as the body begins to slow down. The body doesn't need the energy from food that it once did. The dying person is sleeping more now and not engaging in activities they once enjoyed. They no longer need the nourishment from food they once did.

The body does a wonderful thing during this time as altered levels of chemistry in the body produce a mild sense of euphoria. They are neither hungry nor thirsty and are not suffering in any way by not eating. It is an expected part of the journey they have begun.

ONE TO TWO WEEKS PRIOR TO DEATH

Mental Changes

This is the time during the journey that one begins to sleep most of the time. Disorientation is common and altered senses of perception can be expected. One may experience delusions, sometimes thinking others are trying to hurt them. They may also have a sense of grandeur, thinking they are invincible. They may also experience hallucinations, sometimes seeing or speaking to people that aren't there. Often times these are people that have passed on before them. Some may see this as the veil being lifted between this life and the next.

They may pick at the sheets and their clothing in a state of agitation. Their movements and actions may seem aimless and make no sense to others. They are moving further away from their life on this earth.

Physical Changes

The body is having a more difficult time maintaining itself. There are signs that the body may show during this time:

- The body temperature lowers by a degree or more.
- The blood pressure lowers.
- The pulse becomes irregular and may slow down or speed up.
- There is increased perspiration.
- Skin color changes as circulation becomes diminished. This is often more noticeable in the lips and nail beds as they become pale and bluish.
- Breathing changes occur, often becoming more rapid and labored.
- Congestion may occur, causing a rattling sound and cough.
- Speaking decreases and eventually stops altogether.

A COUPLE OF DAYS TO HOURS PRIOR TO DEATH

The person is moving closer to their destination. There may be a surge of energy as they get closer. They may want to get out of bed and talk to loved ones. They may ask for food when they haven't eaten in days. This surge of energy may be less noticeable but is usually used as a final physical expression before moving on. The surge of energy is usually short lived and then the previous signs become more pronounced as death approaches. Breathing becomes more irregular and often slower. "Cheyne-Stokes" breathing may occur. Congestion can increase; causing loud, rattled breathing.

Hands and feet may become blotchy and purplish (mottled). This mottling may slowly work its way up the arms and legs. Lips and nail beds are bluish or purple. The person usually becomes unresponsive and may have their eyes open or semi-open but not see their surroundings. It is widely accepted that hearing is the last sense to go; so it is recommended that loved ones sit with and talk to the dying during this time.

Eventually, breathing will cease altogether and the heart stops. Death has occurred. They have reached the final destination in their journey.

IMMINENT DEATH: SYMPTOMS AND CONCERNS

Predicting the exact time of death is usually hard. The last hours or days of the dying process can be the most difficult for the patient, family, and physician. Fortunately for a vast majority of patients, the last hours or days are spent in a comatose state, which appears to be a comfortable death. However, for some, the end can be a harrowing process.

Sources of suffering of a dying patient can be classified into three categories; physical symptoms, psychological symptoms (e.g., depression) and existential distress (e.g., concerns about death).

Depending upon the nature and chronicity of an illness, physical symptoms may include:

- Pain
- Fatigue

- Nausea
- Vomiting
- Problems with urination
- Difficulty in swallowing
- Shortness of breath
- Weakness
- Dry mouth
- Change in taste
- Fever

Psychological symptoms and existential distress are also sources of suffering. They, too, can be experienced as unpleasant, can occur on a frequent or chronic basis, and can be perceived as uncontrollable. Most patients at the end of life develop psychological and psychiatric symptoms; either alone or in combination with physical symptoms. Among the many possible psychological and psychiatric complications, the most common are:

- Anxiety
- Depression
- Disorientation
- Disturbance of consciousness
- Dysphonic mood
- Irritability
- Memory impairments
- Restlessness
- Unresolved guilt
- Loss of personal integrity
- Increased dependency on others
- Meaninglessness of continued existence
- Anticipated separation from loved ones
- Fear of death

The person may suddenly become incontinent (unable to control bowel and/or urine elimination). Physical disfigurement may occur. Unless the dying person has a rare infectious disease, family members should be assured that touching, caressing, and holding the body of a dying person, even for a while after the death, are acceptable.

HOW THE CHAPLAIN PREPARES FOR THE LAST HOURS OF LIFE

SETTING

During the last hours of their lives, all patients require skilled care around the clock. This can be provided in any setting as long as the professional, family and volunteer caregivers are appropriately prepared and supported throughout the process. The environment must:

- Allow family and friends access to their loved one around the clock without disturbing others
- Be conducive to privacy and intimacy

Medications, equipment, and supplies need to be available in anticipation of problems, whether the patient is at home or in a health care institution.

As the patient's condition and the family's ability to cope can change frequently, both must be reassessed regularly and the plan of care modified as needed. As changes can occur suddenly and unexpectedly, caregivers must be able to respond quickly. This is particularly important when the patient is at home, if unnecessary readmission is to be avoided.

CAREGIVER PREPARATION

If the last hours of a person's life are to be as rewarding as possible, advance preparation and education of professional, family, and volunteer caregivers is essential; whether the patient is at home, in an acute care or skilled nursing facility, a hospice or palliative care unit, prison, etc. Everyone who participates must be aware of:

- The patient's health status
- His or her goals for care (or the parents' goals if the patient is a child)
- Advance directives
- Proxy for decision-making

Other important aspects of caregiver preparation include:

- Knowledge about the potential time course, signs and symptoms of the dying process, and death (and their potential management)
- Understanding that what they see may be very different from the patient's experience.

If family members and caregivers feel confident, the experience can provide a sense of final gift giving. For parents of a dying child, confidence can leave a sense of good parenting. If family members and caregivers feel unprepared and unsupported they may spend excessive energy worrying how to handle the next event. If things do not go as hoped for, family members may live with frustration, worry, fear, or guilt that they did something wrong or caused the patient's death.

Physicians will need to establish, in advance, whether potential caregivers, including professionals who work in institutions, are skilled in caring for patients in the last hours of life. Don't assume that anyone, even a professional, knows how to perform basic tasks.

UNPREDICTABILITY OF DEATH

Although we often sense that death will either come quickly (over minutes) or be protracted (over days to weeks), it is not possible to predict when death will occur. Some patients may appear to wait for someone to visit, or for an important event such as a birthday or a special holiday, and then die soon afterward. Others experience unexplained improvements and live longer than expected.

A few seem to “decide to die” and do so very quickly, sometimes within minutes. While we may give families or professional caregivers an idea of how long the patient might live, always advise them about the inherent unpredictability of death.

CONCLUSION

Death is still an unknown phenomenon. At the same time we all know that it is the only certainty in life. All living organisms die; there is no exception. However, human beings alone are burdened with the cognitive capacity to be aware of their own inevitable mortality and to fear what may come afterwards. In this enlightened age, man still reacts to death with fear.

Much of our response to death is avoidance. Talking about death on a personal level creates discomfort. Fear and anxiety are among the most frequently used to characterize orientations toward death throughout the life span.

This is because human beings have a basic self-preservation drive. Combining this drive with the realization that death is inevitable creates in them a paralyzing terror of death. But if people realize that they are mortal, they know that they do not have an eternity to complete their projects and that each present moment is crucial. In this way the awareness of death can be the source of zest for life and creativity.

NOTES

Module 3
Hospice Manual
Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. What is the most common misconception about death?
2. Patients who receive excellent pain management tend to_____.
3. The change in dosage to meet patient's needs is known as_____.
4. Sources of suffering of a dying patient can be classified into three categories, what are they?
5. Discuss the states of consciousness as death approaches.

MODULE 4: ROLE OF RELIGION/ SPIRITUALITY

Religion is a prime source of strength and sustenance to many people when they are dealing with death. Different religious theories explain the inevitability and even necessity of death from different perspectives.

The Bible views death in a positive manner. It says “Blessed are the dead who die in the Lord from now on, that they may rest from their labors, and their works follow those (Revelations, 14:13)”. This verse captures well the Christian views about death; that one has to rejoice in death as a means of entering into God’s kingdom, depending on one’s relationship with the Lord.

Spirituality and religion have been reported to play a significant role in managing death anxiety and enhancing a sense of well being, as mentioned by various researchers. Spiritual care affirms and respects the diversity of belief systems and cultural expressions of the patient and family.

Spiritual support may include

- Meditation
- Prayer
- Communion
- Baptism
- Rituals

Whenever requested, chaplains should facilitate a connection to the family’s own faith community and spiritual advisor, but chaplains should always be readily available at the family’s request.

Hospice chaplains are trained to assess and address spiritual pain in patients, and to alleviate it if at all possible. This pain may arise from unresolved relationships with their perception of a higher power or with individuals in the person’s life. It also may be the result of an inability to find and celebrate one’s life’s accomplishments; to know that it matters that he/she walked this earth. There may be some unrest as to what happens at the end of one’s life. These issues and more can be explored with the support and resources of the chaplain.

Chaplains will accompany people through their life questions and help them discover possible answers. If needed, chaplains can help with the planning and performing of a memorial service that is custom-made to match the belief system of the patient and family. If the patient has resided in a skilled nursing facility, the chaplain may arrange for suitable bereavement support for the staff as well.

The Chaplain’s goal is to offer support as the patient and family adjust to changes in their lives and to foster a sense of comfort, safety and peace.

Those who care for the needs of the dying have to attend to at least four different levels at once:

- Emotional

- Ethical
- Religious
- Spiritual

Many chaplains simply identify the spiritual with the religious or just concentrate on ethical or emotional issues. To cover the other-than-bodily concerns of the dying, chaplains must be multifaceted.

Chaplains may find that religious people complain that their spiritual needs are not met by their religion, ethics or psychology. Likewise, they may find non-religious people talking about issues they call spiritual.

At life's end, the dying usually feel the need to ask long-neglected questions about what really counts in life and about dying itself. Many see little meaning in a narrowed and shortened future as they are forced to deal with friends and family in new and embarrassing ways.

Most dying people feel that they have now become a burden. Feeling betrayed by their own bodies, they often picture themselves as ugly, as cast out from the society of the healthy and left to feelings of isolation and abandonment, even self-hatred, fear and anger.

Most caregivers recognize these needs as "spiritual," but few can explain how to respond effectively. This includes not only family members of a dying parent but professional pastoral care workers as well.

Caregivers need the words and ideas that can guide the attention they pay. Field instructors in training programs need to clarify how the spiritual needs of the dying relate to their emotional, ethical and religious needs. Hospice administrators need criteria for hiring effective caregivers. For all these domains of care, we need some precise definition of the spiritual.

WHAT IS "THE SPIRITUAL"?

Most clergy or chaplains think of the *spiritual* as the ways we transcend ourselves that are not based on reason alone. Or, to chisel more precision out of that amorphous term reason, we can think of the spiritual as that realm of our living that goes beyond the insights and values that we can easily explain to one another.

We strategize, plan, analyze, weigh pros and cons, test our ideas on experience, and use logic to make sure we're being consistent and clear. But people facing death are less concerned with what they can account for and more concerned with their hopes, their companionships, and all the happy, baffling decisions they made that opened them up to a richer and deeper life.

It appears that this is what we mean when we refer to "the spiritual." We are speaking of "ultimate meaning." We are speaking of all the ways we are drawn toward a "beyond" throughout our lives, despite the fact that we never fully understand things; transcendent events like these: How art and music symbolize the harmonies that we seek. How falling in love means

taking risks that a rational assessment would not warrant. How we might realize that the expression, "There's more to this than meets the eye" is actually true about everything. How the questions about God and eternity occur even to militant atheists.

Several sages, widely separated in history, identified three remarkably similar ways we approach these transcendent meanings; faith, hope and love.

Paul pointed to these same three events as bringing him to true wisdom in Christ Jesus. Although Paul is the only biblical author who mentions this triad, the fact that it has become enshrined as the theological virtues familiar to Christians today suggests that they represent recognizably distinct features of our consciousness.

Paul was not laying out faith, hope and charity as just cognitional elements in some epistemology. Nor was he proposing them as standards for religious living. Rather he was explaining how they already operate in everyone's consciousness to deal with ultimate meanings. His empirical approach meets the criterion that any definition of the spiritual should make sense to non-religious people yet not exclude religious meanings.

TRANSCENDENT FAITH

Transcendent love means yielding to the pull toward beauty, intelligibility, truth, value and company without restriction. These transcendental subjects have no intrinsic limitations, we can always seek more and whether or not we conceptualize our yielding in religious terms, when we so yield, there is no end to the values we are open to recognizing. This yielding love becomes explicitly religious when we recognize its ultimate value.

The knowledge here is primarily knowledge of values, and only as a result is it a set of truths. When we share love, we reprioritize what we appreciate and what we disparage in the world around us. We see eternal worth in another person; we more quickly recognize a value-rich community when we see one; we more keenly discern which of our hearts' many inspirations we should follow.

We feel empowered to be civil to the uncivil. We take on responsibilities that logic tells us to avoid. Our knowledge of values results in a set of truths, the knowledge of facts we take on belief rather than proof, because we trust the word of those we love. By liberating our minds and hearts to see higher meanings, deeper values, and saving truths, faith lies at the heart of any social or political policies aimed at bringing out the best in us.

Such a functional view of faith seems a better approach to talking about spirituality. It avoids identifying faith with religious truths, and yet it underlies what every religious person holds as true. It also avoids a strict identification of faith with trust in God, yet it includes a trust in transcendent reality under whatever name one prefers.

Hope can be defined as desire rendered confident by this faith. Hope is a desire, not a certitude; a yearning, not a possession. It is confident because transcendent love moves us to believe, often

in the face of horrendously contrary evidence, that the world is not ultimately senseless and that morality is far more than obedience or convention.

Having hope is not the same as having hopes. While we achieve some of our hopes and fall short of others, none of them has the expectancy that makes further hope either superfluous or futile. The dying, in particular, can glow with hope even when their lives are littered with disappointments. Hope is a transcendent kind of knowledge because it anticipates a beyond, a resolution of all chaos, and an ultimate meaning to the universe whatever our personal role in it may be.

Because our minds cannot formulate what this beyond is like, we rely on our imagination to represent it to ourselves. We imagine what our family could be. We visualize world peace. We surround ourselves with symbols of transcendence: the image of blindfolded Justice with her scales; the statue we call Liberty; and the architectural renderings of façades that suggest Security in a bank and Wisdom in a university.

Religious hope works the same way in our consciousness, but it has an explicit object. We imagine God and our life with God. We create sacraments as palpable media for connecting with a God who is Spirit. We paint or carve the images that focus our attention on the divine. We compose the music that lifts our hearts to the ultimately transcendent. We write rubrics for re-enacting and celebrating holy moments. We design churches whose lines and spaces point to the obscure object of our yearning.

Such confident desire can enable a society to withstand the pressures of greed and revenge that precipitate wars. It can energize the individual to try, and try again, in the face of broken friendships, bankruptcy, or the string of slow losses that come with age. It gives healing time for the vision of faith to reverse enmities and gradually build the social systems that reflect human dignity. This functional view of hope can make sense to anyone, religious or not.

The third mode of spiritual transcendence is charity. Only a species of charity will halt the spiral of retribution that prolongs wars, breaks up families and drags civility down to barbarism. Charity releases us from the prisons of our unchallenged opinions by exposing us to the viewpoints of others. It raises questions in us that we never thought of, and it opens up new worlds to us when we find some answers.

It is the spirit of charity that makes a couple out of two egos, a family out of a couple, a neighborhood out of families, a people out of neighborhoods. Charity is no picnic, of course, since we always lose some ego when we embrace the compromises that mutual love entails. Hesitate we may, but we are also drawn. This charity, then, is not first a standard that ethics upholds; it is first an impulse, an allure, and an invitation. We recognize this pull as ultimate precisely because we know very well it could take us anywhere.

The acts of charity are the same for both the religious and non-religious. Even the felt motivation is practically the same. A religious woman doesn't love her neighbor for a religious reason; she feels an impulse to love and she obeys. While she believes that this love is God's gift, she also recognizes that it is ultimately love that makes her life and death meaningful.

SPIRITUAL ISSUES OF THE DYING

Throughout history, the terms faith, hope and charity have become exclusively religious. So, to keep our focus wide enough to include non-religious perspectives, we should translate these three virtues into their correlatives as three "issues." For faith, the issue is commitments; for hope its aesthetics, and for charity, it's about company.

First, consider how commitments are an expression of faith. Faith, the values we embraced out of transcendent love, shows in our commitments. It does not show in every commitment, but only in those where our decisions were motivated chiefly by love. We all have memories of taking a risk because we trusted someone's word out of love. Whether this love was for God, for a friend, or even for a community to whom we feel loyal, in many of the major turns in our lives, we pivoted on our hearts, not our minds.

We may recall decisions to protest injustice or decisions to defend the status quo; decisions to marry and raise a family or decisions not to marry but to live in celibate community; decisions to switch careers or decisions to stay the course.

In conversations with people facing death, these are important events: how big a risk they took, how trusting they were, how courageously they met life's challenges. These form the golden threads gleaming in every person's biography, tying together their lists of places they lived, the awards they received, and the people they met. These stories beg a telling as death approaches. Many people have no experience in talking about their commitments. They just made them, carried by a deep-running love that seemed like still waters to bystanders.

Pastoral caregivers need to raise the topic and learn how to pursue it. They need to be more delicate with those who show no interest in spiritual things, but use gentle persistence with those who seem to have no interest in "spirituality."

Other people facing death feel an acute sense of having avoided commitments that their hearts recommended. This too is about ultimate meaning in their lives, and caregivers can help them address it. The mere willingness to listen can heal this moral wound much like fresh air heals a skin abrasion.

For a typical case, imagine a woman who admits having avoided religious commitment. That doesn't mean she never let herself be moved by love, nor that she consciously shut down all thought of it. At a minimum, effective care can focus on how she followed her heart, particularly on what her heart valued above all, whether or not she names it God.

It is important to keep in mind that the work of giving spiritual care occurs originally and essentially within the caregivers. They need to keep a few central questions in mind about the person before them; questions posed mainly to themselves. Regarding faith, the caregiver's central question about the dying person might be: Where did she let her heart take the lead?

Next, consider how aesthetic experience is related to hope. Usually, it takes images to enkindle hope. Ideas, concepts, and logic leave the heart cold. It takes images to represent what we long

for without seeing clearly. Images, however, are not the only vehicle of hope. Any raw experience that represents hoped-for possibilities will work, as long as these experiences are palpable, significant to the individual, and aesthetically inviting.

For the eye, we need windows that open out on luminous landscapes, artwork with magnetic staying power, rooms and furniture pleasing to the eye and rich in reminders of the transcendent riches of home or healing or adventure or safety.

For the ear, we need places of silence, places where nature can be heard, and listening places for music that lifts the spirit to divine harmonies.

For the hand, we need to notice the textures and the weight of things, considering what deep associations might arise when the dying person handles them.

For the foot, we need to understand what walking means for people who cannot walk far; memory can convey a profound symbolic importance for a man just to stand at a threshold, to venture out, to turn a corner, to explore, or to make it to the sink. Whether he sways in a little dance or abbreviates a bow, he exercises hope.

For the nose, we need places where the smell of urine and feces are contained behind a dignifying bathroom door and evacuated by a good fan.

For the tongue, the image of eating is literally a matter of taste. Tomato soup usually says "home" to an American, but not to the Japanese. For a man in Milwaukee, drinking means beer; for a woman in Toronto, wine. For some, eating means company; for others it's just nourishment.

Obviously, environment counts; whether for nursing homes or hospice facilities or the dying person's home. It requires sensitive attention to individual tastes. Some will want Mozart, others silence. Some want a view of nature, others art classics.

Sometimes, an individual's apparent tastes mask deeper needs. When a dying man's tastes lean to mindless television, a caregiver's gift is to probe deeper to uncover more effective symbols of hope. The caregiver's central question might be: What images and raw experiences give this person hope?

Finally, consider that the essence of charity is found in human company. Charity has unfortunately come to mean just giving to others, something we do easily for fame or a tax deduction. But real charity means both, to give and to receive. It means entering a relationship without control of its future, and not all relationships embody this unnerving sacrifice of control.

Many relationships with colleagues or siblings have little transcendence about them. What distinguishes charity is how it weaves a network of companions in the struggle, company with people who share a sense of the mystery of life, of a common concern for progeny, and of a final destiny that awaits them together.

The love they feel does not have to be restricted to the living. The elderly in particular feel company with friends who have died. Nor should this love be restricted to the human. Religious people need to talk about their love for God and God's love for them. And even non-religious people can swell with gratitude for the gift of being able to love without necessarily thanking God.

Caregivers need to lookout for who really are the main characters in the dying person's transcendent drama, since mere personas often get in the way. More than eliciting stories, though, caregivers also need to be aware of the paradoxical birth of a new charity just as physical death draws closer, the obvious company that the dying person and the caregiver share in this struggle. Their mutual presence is charity alive; it is a common presence to mystery; and though it doesn't need to be talked about, it is important for both parties to feel the blessing and the gift. Aware of the present moment, then, and of the dying person's companions in life's mystery, the caregiver's central question might be: Whose company made her a better person?

PLANNING ACCORDINGLY

The essential work of providing spiritual care happens first in the caregivers. To notice the spiritual needs of the dying, they need to be familiar with these transcendent events. Some may object that they can get this only secondhand, by attending to what dying people express. But all self-transcendence in life involves dying because life's decisions always involve a dying to alternatives.

In these decisions, anyone who cannot see values beyond their logic, mystery beyond their lives, and people beyond their egos, will by default act on mere consistency or pure compulsion. The more they recognize the death in every moment, the better company they will be to the dying and the more readily will they learn life-lessons from them.

A practical service that a caregiver can give is to help the dying tell their stories. This requires an ability to drill down beneath the work histories and the photo albums to uncover the transcendent decisions that committed them to some liberating path in life and to name those friends with whom they shared a keen awareness of a beyond.

Even with religious people, it is important to peel back their religious practices and uncover their commitments and company, including and especially, the company they keep with God. The primary payoff here is to help the dying become more aware and more appreciative of the spiritual dimensions of their lives.

However, there's a valuable secondary payoff as well. By recording these stories, by audio or video tape, or by writing a biography based on interview notes, surviving family and friends would inherit a poignant record of the spiritual depths of their loved one.

One has to realize that death is not the ultimate tragedy of life. The ultimate tragedy is the depersonalization – dying in an alien and sterile area, separated from the spiritual nourishment

that comes from being able to reach out to a living hand, separated from a desire to experience the things that make life worth living, separated from hope.

It's always unpleasant to talk about death and many times no one wants to talk about it. Talking about it may be uncomfortable, painful, and depressing. Death, both our own and the death of our loved ones, is something we will all face sooner or later. For those who will care for a person who is terminally ill, the issues of death and dying become a reality. It is important to be able to discuss both death and grief at some point.

When a loved one is approaching the final stages of a terminal illness, beyond the ability of medicine and doctors, it is common for most people to decide to go home to be with family. During this time, the caregiver and the patient will require a lot of mental, emotional, and spiritual support. Hospice chaplains have a special place here. Hospice may be helpful and necessary to alleviate both the caregiver's and their loved one's problems.

Hospice returns the natural process of dying to the home or home-like setting, amid familiar surroundings and the comforting presence of family. Hospice focuses on caring for the whole person, restoring dignity to the final days. Any terminal illness is considered:

- The patient is terminally ill (less than six months to live)
- The patient chooses to receive hospice care versus hospital or nursing home care
- The patient can no longer care for themselves due to a medical condition

Hospices provide nursing care, medical equipment, drugs, physical and psychological therapy and spiritual services. Hospice utilizes teamwork through the use of medical professionals, home health aides, social workers, chaplains, volunteers and others to make the process of dying as "acceptable" a product of life as possible.

NOTES

Module 4

Hospice Manual

Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. The Chaplain's goal is to offer support as the patient and family adjusts to changes in their lives and to foster a sense of comfort, safety and peace.

TRUE FALSE

2. Hospice is considered for any terminal illness. What are the three criteria described in this module?

3. Those who care for the needs of the dying have to attend to at least four different levels at once. What are they?

4. In your own words, discuss the spiritual issues of dying.

MODULE 5: THE CHAPLAIN'S ROLE IN THE END OF LIFE

The inclusion of “spirituality” in medical practice and research has become increasingly commonplace in recent years. Although clarity as to exactly what is meant by this term continues to be elusive, acceptance of its significance in the care of patients has increased as we continue to gain a better understanding of its role and develop related standards of practice.

End-of-life care has incorporated some consideration of spiritual care since the advent of the modern hospice movement within the vision of Dame Cicely Saunders in England approximately 40 years ago. Her vision of a community of caring that would attend to the spiritual needs of dying patients, along with addressing their pain management and other medical needs in a more humane fashion, was the foundation for the modern hospice movement.

Although much of current end-of life care has evolved from the challenge extended by Saunders regarding appropriate care of the dying, her commitment to meeting the spiritual needs of dying patients continues to be a challenge for healthcare providers.

These challenges grow out of a number of exacerbating factors concerning the diverse understandings of spirituality in a culturally pluralistic society, as well as the complexities of contemporary healthcare delivery systems.

While recent evidence indicates that both patients and their families consider spiritual care to be important in end-of-life care, the understanding of what this means varies considerably. The expectations expressed by the desire for spiritual care are expansive. They can include the spectrum from some sense of an emotionally sensitive care of the “human spirit” to a highly ritualized religious care incorporating very specific rites for the dying and a multitude of possibilities in between.

Even those healthcare providers most sensitive to the inclusion of spiritual care at the end of life may be daunted by the thought of engaging such a fluid and somewhat nebulous expression of need.

Two primary aspects of palliative care are (1) an understanding of the virtue of caring (in contradistinction to curing) as a practice of medicine and (2) an appreciation of the art of listening well in the care of patients.

Both of these resonate with the provision of spiritual care to the dying, and their central roles in palliative care speak to the potential for palliative medicine to remind all of us of the importance of listening and caring as essential aspects of practice throughout all of medicine, not just with the dying.

The resolution of who can best provide intentional listening, as well as interpret the stories and struggle faced by those considering their mortality while reviewing their lives for a sense of purpose and closure, is not the same for every person.

Those who render such care must examine themselves regarding their capacities and willingness to engage the rich and textured complexities of those for whom there are no illusions of cure, but who none the less need their undivided attention at the junction of life and death.

The development of the skills and capacity to do such work has not been a standard part of medical education and patients have suffered for this inadequacy. As human beings, we listen to the voices of suffering, especially the voices of those who know they are dying and their families, and we become poignantly focused.

Along with asking challenging questions regarding prognosis and other “medical” inquiries, they become seekers and purveyors of “spiritual” understanding and wisdom. The language used for such communication will frequently be very specific to a particular cultural or religious tradition.

While considerable strides are being made in improving communication skills for physicians in the care of the dying, lack of familiarity with such tradition, specific language and metaphors through which a dying person expresses her “soul” can limit the capacity of the physician or other provider to listen well.

This lack of familiarity is not a fault in the provider, but acknowledgement of this lack and seeking the assistance of someone more versed in the tradition of the dying patient can be crucial for providing meaningful spiritual care. Awareness of one’s lack of familiarity with the religious or cultural tradition and language of a patient may not be readily evident, and patients may be hesitant to point out such gaps of understanding.

Only through our attentiveness to the patient’s story and the humility to discern our own inadequacies will we best serve the communication needs central to providing optimal spiritual care for dying patients.

The best spiritual care for the dying is most likely to be delivered in the same way other types of care are best provided, through partnerships within the team of persons caring for the patient.

Although much of medicine is best practiced within a context of teamwork, palliative care particularly denotes a team approach and vital to a palliative care team is the clergy member of the team or the chaplain.

While many physicians, nurses, and social workers have substantial gifts to offer to the spiritual care of patients, the role of a clergy member on the team to give leadership in providing spiritual care cannot be overstated.

The other providers on the team may have a greater appreciation of the particular faith tradition of a patient and may serve as the more trusted spiritual confidant and care provider, but the clergy member of the team brings an interpretive, liturgical, and communal sense of spiritual care from his pastoral formation unique to that vocational formation.

The optimally trained and wise chaplain provides pastoral services within the entire community surrounding the dying patient and fosters a sense of care for one another that acknowledges the

interdependency of the providers, the family, and the dying person in this work of living and dying. Healthcare providers rarely fully attend to the role of this interdependency in forming the health of the community, which ultimately determines how we care for the suffering and dying among us.

“Health is not just the sense of completeness in ourselves but also is the sense of belonging to others and to our place; it is an unconscious awareness of community, of having in common.” Mindfulness of our interdependence allows us to be less captive to consumerist expectations and their distortion of caring relationships, while nurturing a greater sense of gratitude within an awareness of the limitations and finitude of healthcare.

Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and, at the same time, honor the privilege of intentional and reverent caring for the dying. Good spiritual care is not just calling the chaplain for last rites or prayer with the bereaved family near the time of death.

Although these are both valued and legitimate aspects of spiritual care, they fall short of the vision for spiritual care indicated by a comprehensive strategy for palliative care. Spiritual care should inform the practice of palliative care throughout the course of treatment.

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 the time to make peace with one’s neighbor and with God while supported emotionally by family or friends.

WHY IS SPIRITUALITY IMPORTANT?

Spirituality and religion are important to patients and families: Recent polls conducted in the United States indicate that patients and families are requesting increased attention to the spiritual dimension of their lives by health care providers, especially at the end of life.

These spiritual issues and concerns are often (though not always) asked and answered with reference to a religious framework of meaning, consequently, it is important for chaplains to; learn about the religious beliefs and practices of the patients and families in their care, assess the role of these beliefs and practices in health care decisions, integrate these spiritual beliefs and goals into the overall plan of care.

The spiritual role of the health care provider is crucial to care of the whole person at the end of life. The focus of care is the whole person and family. The explicit goal of care is to alleviate, not just physical pain, but social, emotional, and spiritual suffering. Increasing expertise in the area of spirituality and religion becomes not only a professional but a moral obligation

TWELVE REASONS TO ASK ABOUT RELIGIOUS BELIEFS AND PRACTICES

1. Because health care decisions are made by persons who are at once physical, emotional, relational, and spiritual beings
2. To respect the beliefs and customs of patients and families
3. To provide care that is truly patient and family centered
4. To respond to the widespread request by patients for attention to this area by their medical caregivers
5. To build trust and respect religious customs and beliefs
6. To provide an opportunity to inform patients/families of the interdisciplinary care available to them (See section *About Hospice Care* for more information.)
7. To better distinguish religious experience and belief considered normative from pathological behavior or belief induced by medications, abnormal grief, or disease progression
8. To better understand when a conflict might occur between goals of medical treatment and patient values/beliefs
9. To accurately identify and treat total pain
10. To help patients draw upon resources that might help them cope with unrelieved physical pain or other symptoms and/or to identify non-physical causes of this pain
11. Because the end of life raises spiritual questions for the majority of persons
12. Because people's religious/spiritual traditions have established rituals and beliefs that influence health care choices, bring comfort and meaning, and facilitate closure or transition at the time of death

CHAPLAINS OFFERING HOPE

The hospice chaplain has the opportunity to work with cultures or groups of people in virtually every religion (Buddhism, Christianity, Confucianism, Hinduism, Islam, Judaism and Taoism to name a few) including many variations of each religion. Chaplains will also work with agnostics and atheists (who are spiritual in their own right, since they have invested extraordinary thought into "not being religious.")

Regardless of beliefs, when people make the hospice decision they are choosing to live out the rest of their lives with dignity.

People are freed from enduring further medical procedures that are not arresting the disease. Medical intervention for symptom management takes the front seat. The renewed focus is on acceptance, care, comfort, dignity and a sense of peacefulness that stems from the very core of their being – their soul.

The body is the "apartment" for our soul. Although our physical body is failing, our soul may thrive. The language of our soul is meaning. We may re-discover our soul when a poor medical prognosis awakens a need for deeper meaning in us. Spirituality, or life meaning-making, becomes front and center at perhaps a deeper level than before.

In hospice, the patient is back in charge with the support of loved ones and the hospice interdisciplinary team: physicians, RNs, home health aides, social workers and chaplains. Team members travel to the patients' homes, wherever "home" may be: private residence, assisted living, skilled nursing facility or hospital.

Hospice chaplains can assist the family in completing their "unfinished business." And the patient chooses which sort of help they wish to accept. The patient always has the right to accept or refuse certain treatment plans, medications or counseling. The patient and family as a unit have control of the plan of care.

Hospice is about living, not dying. The focus is on the distinction between curing and healing. While curing eliminates disease, healing focuses on wholeness and peacefulness as we journey toward the end of life. Curative measures may see death as failure. Healing includes death as one of the sacred, natural outcomes of life.

We connect with our vulnerability when we identify our needs for wholeness. Our journey may include releasing old hurts through forgiveness of ourselves and others. We recognize that forgiveness is a gift to ourselves. It does not suggest that we are compromising our dignity or our sense of right or wrong. Rather, we are claiming peacefulness for ourselves – setting our soul free from spiritual unrest.

Re-claiming wellness includes embracing freedom from devastating medical diagnoses. We own our terminal diagnosis, while at the same time, we claim healing as we work toward our sense of peacefulness. In this process we may begin to deepen and transform our understanding of hope.

Hospice engages hope. It does not let go of hope. I believe God is our infinite, self-renewing source of hope. Our hope may transform as our healing deepens. Our hope may be to have time alone with each of our loved ones. It may be to reconcile a relationship that fell off the track somewhere along the way in our lives. We may have come to realize that it is a relationship we hope to rekindle as part of healing.

Our journey toward peacefulness may involve anger along the way. But is it really anger. It certainly sounds like anger! It may be anger. Anger is easier for us to access than our sadness. It may be profound sadness.

I often sit with patients or family members in silence. I think of it as "relational silence" because there is an awful lot going on. It isn't being articulated, but it is voiced through sacred silence. "Be still and know that I am God!" (Psalm 46: 10a).

When we release our loved one to go, it is an expression of wellness or healing. As a loved one, we face anticipatory grief during this time. It is profoundly sad to be left behind. Perhaps the deepest expression of love is to give our loved one "permission" to go when she or he is ready.

Life is forever altered when a loved one passes on. We learn to carry our grief as part of who we are. We cherish the beautiful gifts that our departed loved ones have given us – gifts of who they were and how they loved us. As people who have been left behind, we own those beloved, intangible gifts forever. In recognition of this trying time, hospice follows patients, families and loved ones for thirteen months following death. Support groups may be available indefinitely.

Hospice is a gift we give ourselves once medical treatment modalities are no longer helpful. A peaceful passing with the hospice patient is a drawing in and eventual surrender to God. It is natural. It is sacred. What a deep privilege it is to serve in this resilient ministry of life.

ADEQUATE SPIRITUAL CARE

Adequate spiritual care helps provide the context for a good death for the dying person with attentiveness to that individual's particular needs. Spiritual care as part of a comprehensive strategy for palliative care provides the opportunity and support to narrate one's story in such a way as to provide a legacy and memory of a "good death" for the family and broader community.

The spiritual legacy of such a narrative can be a gift for generations to come and reframes the inevitable experience of loss within death as a reminder of the gift of the life that has been lived. The importance and value of well-trained clergy or chaplains as partners in providing the hope of a "good death" and its legacy is evident, but the lack of availability of such persons is all too common.

Recent collaborative efforts between the Pastoral Services Department at Duke University Medical Center and the Duke Institute on Care at the End of Life to train specialist chaplains in end-of-life care are an attempt to address this issue. While the equipping of more specialized chaplains for tertiary care centers is helpful, the large numbers of persons dying in smaller hospitals without staff chaplains require everyone's consideration.

If we are convinced of the value of spiritual care as a part of palliative care and believe clergy to be important in the rendering of that care, we are challenged to consider how to best address this void of spiritual care providers in smaller hospitals and communities.

Spiritual care is finding its place as a practice in healthcare. Standards of practice for spiritual care have not been developed and we are still unsure as to just who should be engaging in its practice.

Spiritual care has been part of end-of-life care since the start of the modern hospice movement, but it continues to evolve in content and form in response to increasingly pluralistic societies in the United States and Western Europe.

Providing spiritual care with integrity to the faith tradition of the dying patient can be challenging, but such care cannot be viewed as an optional luxury within the developing discipline of palliative care. The substantive shared commitments of good spiritual care and palliative care bear witness to spiritual care being inherently constitutive of palliative medicine rightly construed.

Support for intentional spiritual care as an integral part of quality end-of-life care should come from many quarters, but support and commitment to spiritual care's place in palliative care at the end of life must come from physicians and administrative leaders in palliative care. The health of us all depends on it. As part of the hospice healthcare team, hospice chaplains make spiritual care a priority. Chaplains offer open, sensitive, and non-judgmental presence and an acceptance of different beliefs, cultures and values.

Chaplains are called on to support every family with as much compassion and care as possible. Being able to walk with someone as they die is an incredible gift. We must recognize this gift and respect life in all its stages and transitions. The chaplain's hope is to share in this incredibly sacred time in such a way as to provide spiritual healing, purpose and meaning honoring each patient entrusted to our care.

Issues of meaning, spiritual pain, forgiveness, hope, and relatedness become more focused during terminal illness. Supportive presence, listening, and appropriate intervention given by a hospice chaplain can help make this time a blessed time.

Hospice Chaplains provide some of the following:

- Care to patients, families and caregivers according to their desires and beliefs.
- Assistance connecting people with clergy of their own faith group or other professionals.
- Open, sensitive, and non-judgmental presence accepting of different beliefs, cultures and values.
- Assistance in making arrangements for, or officiating at, funeral or memorial services; cooperating with church and non-church families alike.
- Regular visits in the hospice house, giving patients and families a chance to get to know the Chaplain over a casual cup of coffee shared in a home-like setting.
- In-Home patients can expect to receive a call from a hospice Chaplain within seven days of admission into a Hospice program.
- From initial visit forward, Chaplains continue to visit or just be available to call, talk, visit and offer support.

Hospice chaplaincy is a unique style of ministry. Unlike traditional faith community service and hospital ministry, end-of-life spiritual care helps terminally ill patients from all faith traditions bring closure to their lives and cut free from sentimental places and sacred things.

But tending to the pressing needs, recurring wishes, and relentless demands of patients that are getting acquainted with society's most feared subject is only part of this courageous ministry. Hospice chaplaincy also helps family members rediscover hope, purpose, and vision as they relinquish their dying loved ones.

While providing compassionate care, hospice chaplaincy must follow stringent state and federal regulations, as well as company guidelines that are in constant flux. Keeping current with changing policies and evolving procedures can generate ongoing stress for many spiritual caregivers.

Spirituality addresses the meaning of our lives...our contentment with our lives. It is a part of each person's being. At the end of life it may be important for some of us to see that our lives have mattered and that we have made a difference. Spiritual peace can make death more meaningful and acceptable. Hospice Chaplains can help hospice patients explore the meaning of their lives and find peace with who they are and with death.

All hospice patient and/or their family members and friends are offered the spiritual care services provided by the Hospice Chaplain. Spiritual care is anything we say or do that helps the spiritual and/or emotional nature of a person for their enrichment and comfort.

Spiritual care services are provided regardless of the patient's faith or beliefs. The Hospice Chaplain is available to visit patients in their homes, hospitals, or in nursing homes. Often the Chaplain spends as much time caring for the family as he does with the person receiving hospice care. In hospice, the entire family becomes the focus of care.

Some hospice patients have already addressed their spiritual needs and may not need the Hospice Chaplain, but the Chaplain is available throughout the process if the need arises. The Chaplain can work in conjunction with a hospice patient's own pastor, supplementing that pastor's role when needed.

The Chaplain is available to visit with hospice patients and get to know them, pray with them, and to discuss any spiritual concerns that they may have. Visits are scheduled based on the patient's wishes and state of health and usually last 15 to 30 minutes, depending on the patient's desires.

HOSPICE CHAPLAIN DUTIES

Hospice chaplain duties and spiritual care responsibilities are outlined in this sample job description, defining the role of a hospice chaplain when meeting the spiritual care needs of patients facing the end of life. This sample job description is not comprehensive, there may be other functions required on a case by case basis.

- Serve as a well known member of the hospice team.
- Complete spiritual assessments for patients.

- Work with staff, clergy and community groups to enhance their sensitivity to the spiritual concerns of patients / families experiencing terminal illness or loss.
- Participate in patient care conferences by exploring and assessing the spiritual needs of patients / families.
- Maintain contact with community clergy regarding patients' spiritual needs as needed.
- Manage the provision of bereavement services in accordance with hospice policies and Federal Hospice and State Hospice regulatory requirements.
- Maintain proper documentation of pastoral care visits to patients and their families.
- Perform occasional liturgical assignments and monthly memorial services with staff when requested.
- Conduct or makes arrangements for funeral or memorial services when requested.
- Develop and maintain a resource group of clergy to whom specific aspects of spiritual care may be delegated.
- Serve in on-call chaplaincy services when requested.
- Provide educational programs for hospice staff, community clergy, religious and lay representatives as appropriate.
- Provide direct spiritual support and end of life counsel to patients and families in keeping with the spiritual beliefs of the patient and family.
- Other duties as assigned by the Director of Spiritual Care.

Spiritual services encompass a lot. In addition to support, guidance and counseling, they can include prayer and worship services as well as rituals and traditions that honor a patient's faith.

Hospice chaplains counsel patients and their families with regard to spiritual concerns. Many patients who take advantage of the spiritual services provided through hospice find that the chaplain helps them gain a better perspective, alleviating some of their depression and stress.

Others consider their spirituality very private and are not comfortable discussing such matters with loved ones. In these instances, a chaplain can provide an outlet for needed conversation about end-of-life concerns.

SPIRITUAL GUIDANCE

Hospice chaplains visit patients in their homes when a visit has been requested. Some patients may need to ask for forgiveness while others question God's reasoning for their illness, and so on. This is when a chaplain can help most.

Hospice chaplains are experienced to deal with these types of situations and can provide relief to the patient and family members who are struggling to cope with the terminal diagnosis.

One thing patients should always expect with hospice, regardless of their spiritual choices, is that they maintain control over their own care. A hospice chaplain should never pressure patients into medical care that they do not want. No matter what their personal religious beliefs, hospice chaplains are trained to respect patients' personal values and wishes.

Hospice patients aren't required to see a chaplain. Engaging spiritual services is optional. It is a personal choice, and patients can change their mind at any time. Many patients decide against it initially, and later realize it's something they could benefit from and choose to take advantage of the service.

Hospice chaplains don't take the place of the patient's minister or pastor. They can choose to seek guidance from their own spiritual counselor, the hospice chaplain, or both. The chaplain will work alongside any church leader to ensure the patient receives all the support they need.

SPIRITUAL COUNSELORS

As interest in spirituality has increased in professional literature, demographic trends in the United States similarly indicate a growing need for information and understanding about death and the dying process. As a demographic force, members of the Baby Boom generation – those born between 1946 and 1964 have changed each life stage they have entered.

While Boomers, as a whole, are not currently considering their own deaths, many are now facing the decline and deaths of their parents. "When 75 million people confront an issue, it becomes culturally significant". It is prudent for the counseling profession to be prepared to provide competent guidance as an increasing number of people encounter the issue of dying, first for their parents and then for themselves.

The spiritual needs of the dying concern professional counselors for two reasons. First, both long-term care of the dying and bereavement represent stressful and spiritually provocative situations for both the dying and their caregivers. Second, because the rate of death is expected to accelerate in the United States over the next 50 years, increasing numbers of people will experience these spiritually challenging and emotionally difficult situations.

This demographic, combined with an increasing interest in spirituality in the counseling literature, indicates that competence in understanding the spiritual needs of the dying will be helpful in providing competent counseling to an enlarging clientele.

SPIRITUALITY AND DYING

Existential theorists consider death as one of four ultimate concerns of life, along with personal isolation, meaning-making, and freedom. The process of facing death inextricably involves the other three concerns, most particularly the process of meaning-making.

According to existential theorists, life and death are continuously co-existent, intertwined with one another. A confrontation with one's personal death ('my death') is the nonpareil boundary situation and has the power to provide a massive shift in the way one lives in the world.

Recognition of death contributes a sense of poignancy to life, provides a radical shift of life perspective, and can transport one from a mode of living characterized by diversions, tranquilization, and petty anxieties to a more authentic mode.

ADDRESSING THE SPIRITUAL NEEDS OF THE DYING

The primary goal of addressing the spiritual needs of the dying is to provide appropriately comprehensive care for the whole person. To address physical and emotional needs alone, but neglect the existential, meaningful components of the dying process, is to provide incomplete and dissatisfying care to an individual who is confronted with the ultimate questions of life.

As physical symptoms, such as pain management, come under control, other dimensions of life become increasingly important. The provision of comprehensive spiritual care for dying individuals includes seven goals:

- Provide culturally sensitive care
- Increase quality of life
- Alleviate anxiety
- Provide comfort and personal contact
- Promote meaning, significance and hope
- Promote informed decisions congruent with spiritual values
- Increase caregiver confidence

Providing culturally sensitive care involves a respectful inquiry about the dying patient's belief system, past spiritual experiences, and current spiritual needs. To use these spiritual conceptualizations with patients will require a comfort with the idea that there are diverse ways of expressing spirituality by the many diverse peoples in the world.

Culturally sensitive approaches to providing spiritual care by counselors includes thoughtful investigation of the client's religious traditions, personal spiritual development, and spiritual memories, such as memories of conversion experiences, of disillusionment experiences, and of values inherited from ancestors and cultural history.

Consideration of how the patient's personal spirituality may differ from his or her cultural history or traditional religious expectations may help the patient achieve reconciliation and a sense of peace with his or her upbringing.

WHEN TO ASK ABOUT SPIRITUALITY

Assessment of religious / spiritual frameworks and needs by physicians, nurses, and other care providers can take place at various stages during the course of the relationship with a patient and family:

- In the course of non-crisis care
- At the time of initial diagnosis of life-threatening illness
- At the time of admission to hospice/palliative care
- In response to signs of spiritual suffering, possible indicators of which include:
 - Fear
 - Hopelessness
 - Guilt
 - Asking questions such as "Why hasn't God taken me yet?" or "What have I done to deserve this?"
- As complex treatment decisions are faced regarding:
 - Artificial nutrition
 - Use of radiation or chemotherapy
 - Removal of life support
 - Use of antibiotics
- When the time of death draws near

In any case, it is important to understand why you should ask.

WHAT TO BE PREPARED FOR WHEN YOU ASK

Assessment of religious/spiritual beliefs and needs is an exceedingly elusive and sensitive area. These may be considered to be very personal questions. Do not be surprised if you encounter some initial resistance or mistrust, especially if the patient/family adheres to a religious tradition with a history of persecution

Although patients and families want their physicians and care-takers to take interest in this area, they are seen as experts in their field. They may even be perceived as threats to the experiential knowledge of the spiritual realm and to religious authority. For example, persons with a strong belief in faith healing may respond to news of their terminal illness by saying, "What does the doctor know anyway, he's not God". Some spiritual traditions accept the need for specific treatments by Western medicine – such as surgery to remove a tumor – but would look to their own healing practices for treatment of other diseases such as a "weak heart".

During a visit with a patient and family, physical and medical needs will demand most of the physician's time and attention. Little room may be left for discussion of spiritual issues if the patient is in physical pain or has received an overload of medical information related to treatment options and prognosis.

Possible ways to address this include consultation with other members of the interdisciplinary team to review relevant religious beliefs. Chaplains should plan to follow-up with the patient and family at a later time to discuss these issues.

CHAPLAINS HELPING TO FIND and ASSESSING HOPE

Hope is a fragile thing. At one and the same time, a patient or family member may accept the news that no curative treatment remains, yet still proclaim that they will "beat this". Coming to terms with a terminal prognosis is a process. The chaplain can help patients and families identify other objects of hope.

To assess a patient's or family's sense of hope, you might ask, "Are there other things you are hoping for during this time?" Some suggestions you might offer include:

- Hope to not be in pain
- Hope to be treated with dignity
- Hope that their family will be ok
- Hope to be remembered well
- Hope they won't be abandoned
- Hope to go to Las Vegas one last time
- Hope to see their son graduate from college
- Hope to find peace
- Hoping for death
- Be aware that for some religious persons hope may lie in:
 - Being forgiven by God
 - The promise of life after death (heaven or reincarnation)
 - Reunion with deceased loved ones

Temporary despair or hopelessness is a common and understandable response to finding out that one is terminally ill, that no curative treatment remains. Persons need time to grieve the many losses that accompany this prognosis. Moving on to other objects of hope too quickly may short-circuit this process.

Some religious persons may feel as if God has not answered their prayers or even abandoned them when news of terminal diagnosis is received. This may cause a crisis of faith and a referral to a chaplain may be appropriate at this time.

Perhaps most challenging to medical professionals is when a patient or family member accepts the news that the doctors have run out of curative measures, accepts palliative care or hospice and yet holds firm to the belief in a miraculous (divine) cure.

Hoping for death is normal, sometimes; the only hope is that there will be an end:

- To suffering
- To what is experienced or perceived as a pointless existence
- To life itself

Many persons feel as if they are weak or that it is unacceptable to wish they were dead; yet it is a common experience for persons with terminal illness. Chaplains can do many things to help those who hope for death.

- Normalizing the wish for death
- Confirming that a person is indeed growing weaker or that they have multiple symptoms that indicate that death is near
- Merely stating that they know this will not go on forever

SPIRITUAL PAIN / SPIRITUAL SUFFERING

Dame Cicely Saunders, founder of the modern Hospice movement coined the phrase “total pain” to refer to physical, spiritual, emotional kinds of suffering commonly experienced by persons with life-limiting illness and their families.

Physical pain itself can be exacerbated by non-physical causes such as fear, anxiety, grief, unresolved guilt, depression, and unmet spiritual needs. Likewise, the inability to manage physical pain well can be due to emotional or spiritual issues. Persons may refuse pain medication due to fear or because they wish to be alert to interact with loved ones or because they believe they deserve to suffer. Unrelieved physical pain, among other symptoms, may itself cause emotional or spiritual suffering.

Finally, some emotional or spiritual suffering, especially in certain cultures, may manifest itself as physical pain or other physical maladies. Spiritual frameworks and religious traditions influence how persons interpret and experience physical pain. How mind, body, and spirit are understood in relationship to each other and, in some cases, in relationship to a deity or deities is important to understand. Usually this framework is broader, to include suffering of all kinds, whether its cause is physical or due to other causes.

Sometimes, these cultural and religious interpretations of pain and suffering can conflict with the stated goal of palliative care: to relieve pain and suffering. This is why a holistic, interdisciplinary assessment of pain is necessary. Plans to manage pain pharmacologically often fail, or patients do not comply with these plans, when the larger spiritual framework is not adequately understood and integrated into the plan of care.

Spiritual practices may help in the management of physical pain. Increasingly, medical staff recognizes the palliative nature of religious and spiritual practices. Some practices that have been proven to help in the management of physical pain include:

- Prayer
- Relaxation techniques
- Chanting
- Ritual cleansing
- Acts of atonement
- Shamanic treatments
- Acupuncture
- Herbal remedies

Spiritual pain and suffering may be caused by physical pain and other symptoms:

- Loss of personhood
- Despair
- Feelings of abandonment by God
- Requests for assisted suicide

Assessment should include attention to spiritual suffering when pain is identified.

Once the physical pain is better managed, the interdisciplinary team should explore whether there is any spiritual pain remaining. Spiritual pain and suffering not caused by physical pain or other physical symptoms is common for people with life-limiting illnesses and for their families.

The knowledge that a person is dying may evoke:

- Anger
- Loss of hope and meaning
- Shame or guilt
- Grief
- Fear

A holistic pain assessment, therefore, should be conducted whether or not the person is manifesting any physical symptoms:

SIGNS OF SPIRITUAL PAIN/SUFFERING

EMOTIONAL

- Restlessness/agitation/anxiety
- Denial of illness or of reality of prognosis
- Anger
- Fear
- Powerlessness and loss of control
- Depression/flat affect
- Dreams or nightmares

BEHAVIORAL

- Refusal to take pain medication
- Refusal of assistance with activities of daily living (ADLs)
- Power struggles with caregivers or family

- Puts self in unsafe care position
- Frantically seeks advice from everyone
- Active forms of self-harm
- Loss of independence
- Lack of engagement with activities that bring comfort or joy
- Withdrawal/Isolation
- Questions about “why” or duration of dying process
- Statements about “not wanting to be a burden”
- Metaphorical or symbolic language suggesting distress or unresolved concerns
- If history of religious practice/affiliation, refuses religious leader or stops practice

PHYSICAL

- Unrelieved pain
- Shortness of breath
- Sleeplessness
- Other signs
- Conflict between the goals of palliation and religious beliefs
- Fixation on nutrition, herbal remedies, or miraculous cure

THE OPPORTUNITY FOR SPIRITUAL GROWTH AT THE END OF LIFE

Although a terminal illness may be perceived or experienced primarily as negative or devastating, for many persons it becomes an opportunity for personal growth and healing. In its Greek origin, the word “crisis” includes a sense of possibility, connotes opportunity. Spiritual growth at the end of life is possible for all persons regardless of belief system.

Persons need not share a religious or philosophical framework that says that good can come out of difficult times or life out of death in order to experience growth and healing at the end of life. Spiritual growth does not diminish suffering. Contrarily, that some healing happens does not diminish the very real suffering experienced both by the person who is terminally ill and by their family.

What precipitates personal and spiritual growth at the end of life? As persons are less able to engage in life activities due to functional limitations, they have time for spiritual reflection and spiritual practice. Dependency, loss, fear, and suffering will lead many people to turn to (or return to) their religious traditions for meaning, strength, and comfort.

- Individual may take emotional and spiritual risks they would otherwise avoid.
- Because family members will not have another opportunity with their loved one, they often seek healing, connection, and reconciliation.
- Facing death evokes spiritual questions (about forgiveness, afterlife, the value of life itself) not normally asked in the course of daily living.

How can the palliative care team help facilitate personal and spiritual growth for patients and families at the end of life?

- By treating physical pain and other symptoms so patients and families have room to focus on relationships, life review, and spiritual practice.
- By offering assistance in finances and insurance matters and providing respite to limit caregiver stress.
- By helping the patient and family identify spiritual, relational, and emotional “goals” or “tasks” in addition to the management of physical pain.
- As an “outsider,” by noticing opportunities for healing and growth in the course of an illness that the patient and family might overlook.
- By asking whether their spiritual, philosophical, or religious framework offers comfort, meaning, or direction for action.
- By sharing stories of how other patients and families have found meaning, hope, and healing during this time of life.
- By being emotionally and spiritually “present” in the face of suffering and despair.
- By inviting the participation of the psychologist, social worker or chaplain.

ASSESSMENT TOOLS AND OPPORTUNITIES

Visual cues indicating possible religious or spiritual beliefs and practices may include:

- Representations of religious figures or community leaders
- Religious symbols or art
- Prayer books or scriptures
- Books about the meaning of illness or healing practices
- Religious clothing such as a prayer shawl
- Altars or shrines
- Herbal remedies

Any other objects considered sacred, invested with healing powers, or used for specific religious practices. These items may be:

- Found in a person’s home
- Brought to the hospital
- In some cases, worn

Special Note: It is always wise to explore what meaning various items may hold for a patient or family rather than drawing direct assumptions about a person's religious orientation.

LANGUAGE AS AN INDICATOR OF SPIRITUAL / RELIGIOUS FRAMEWORK

As patients and families ask questions about their illnesses, discuss treatment plans, or carry on casual conversation, listen for phrases suggesting explicit religious beliefs such as:

- “If God wills it.”
- “It is in the hands of the man upstairs.”
- “This medicine is a blessing.”
- “When she makes her transition...”

Also pay attention for statements that speak to a more general philosophy about illness, fate, or the value of life such as:

- “You play the hand you are dealt.”
- “He’s always been a fighter.”
- “There are some things worse than death.”

As people share pieces of their life stories, their core values and perspectives are likely to emerge.

LANGUAGE AS AN INDICATOR OF SPIRITUAL SUFFERING

Some commonly heard statements that may indicate spiritual suffering include:

- “What’s the point of living like this?”
- “Why is God doing this to me?”
- “I just wish I were dead.”
- “Can’t you do something?”
- “When she gets better...”

Questions asked that seem to be purely medical may, in fact, also indicate the existence of spiritual suffering. For example, when a family member asks “How much longer?”, they may:

- Be seeking factual information regarding prognosis
- Need to know in order to plan for the patient's care needs
- Be doubting their own ability to cope emotionally, or
- Perceive that the patient is experiencing prolonged suffering

UNRESOLVED ISSUES OR UNMET SPIRITUAL NEEDS

Much has been written about the unique language of dying persons. Cultures where it is customary to speak indirectly about sensitive topics often use coded words to talk about illness, dying, and the deceased.

Many ill persons, regardless of their cultural background, will use language and images whose meaning should not to be taken literally. In some cases, this language may refer to a set of religious beliefs or a spiritual understanding of the world.

For example, “I am ready to go home,” may indicate that the person wants to leave the hospital and die in their own house. It may also refer to heaven or paradise.

PHYSICAL SYMPTOMS INDICATIVE OF SPIRITUAL SUFFERING

Sometimes physical symptoms, including physical pain, are entirely physiological or organic in origin and should be treated pharmacologically. However, many symptoms may also indicate the existence of untreated emotional or spiritual pain.

Untreated emotional or spiritual pain should be suspected in cases where symptoms include:

- Physical pain that is unrelieved after extensive and appropriate pharmacological interventions
- Pain that is unspecified or that frequently changes location
- Anxiety
- Increased shortness of breath
- Restlessness or agitation
- Fatigue
- Flat affect or withdrawal
- Insomnia

BEHAVIORAL CUES TO UNDERLYING SPIRITUAL SUFFERING

- Declines assistance with personal hygiene and basic care needs
- Power struggles with family members or caregivers
- If history of practice/affiliation, refuses religious leader or stops religious practices
- Isolation, withdrawal from primary relationships
- Declines pain medication when physical pain present
- Lack of engagement in activities that bring comfort or joy (even when functionally able to do these)
- Family members continue to offer food by mouth even when informed of risk of aspiration

QUALITY OF LIFE

Increasing quality of life through spiritual care of the dying includes providing the opportunity to discuss what one does and does not want to happen in the way care is provided. By giving patients the opportunity to talk about life in spiritual terms, the chaplain adds to the patient's understanding of what is happening currently, and what he or she would like to happen in the future.

The concept of a psychologically "healthy" death requires the active participation of patients to communicate their needs. For example, if a patient becomes aware of a need for confession or forgiveness when giving spiritual consideration to his or her current life, a chaplain can arrange for a consultation with the patient's spiritual leader (pastor, priest, shaman, rabbi, imam) to provide a culturally appropriate ritual within the patient's religious tradition.

Likewise, whether the chaplain promotes the calmness and quiet of a Buddhist death, or provides for an opportunity to extend or receive forgiveness in a Christian death, each fulfills an important aspect of "seeking closure" in one's dying process.

PROVIDE COMFORT AND PERSONAL CONTACT

By providing comfort and personal contact, the chaplain provides the dying person a safe environment in which to consider spiritual aspects of the dying process. The faith based counselor / chaplain, by spending time in conversation with a dying person provides an important function for them, in that the chaplain bears witness to the person's story, spirituality, meanings, memories, and values.

The accepting, validating, personal contact provided by a chaplain may be unique among the patient's circle of caregivers. While other caregivers may be pressed by their own anxieties or demanding schedules, the attentive presence of a chaplain allows the patient to feel accepted, to be comforted, and to process spiritual needs without undue concern for the chaplain's welfare.

Bearing witness to the patient's situation has profound spiritual implications because the patient becomes aware that the chaplain acts as a "container" for his experiences, and that the chaplain may carry those experiences into a future which does not include the client. The opportunity to have one's experiences and spiritual values be remembered and validated can be a significant source of comfort for a dying patient.

MEANING, SIGNIFICANCE AND HOPE

By allowing the patient time and space to process his or her story, the chaplain / counselor provides an opportunity to discover a new sense of meaning in the patient's experiences. For example, a patient may report, "I have learned not to take things for granted, and to treasure even very small acts of kindness."

Processing the meaning of one's death in a purposefully spiritual way allows the patient to gain a sense of personal significance, or an idea of where and how he or she belongs to a larger human story, whether in one's immediate family, or in the larger community.

A sense of hope may be achieved by considering the dying process in terms of one's ultimate future, one's legacy, or a sense of significance in the meaning of one's life and one's relational effect on others.

Faith based counselors, through a culturally sensitive process, can give patients the opportunity to discover and articulate a sense of meaning, significance, and hope by giving patients the opportunity to discuss their dying process in spiritually specific terms, such as forgiveness, reconciliation, acceptance, interpersonal relationships, and the patient's relationship with God.

INFORMED DECISIONS CONGRUENT WITH SPIRITUAL VALUES

Faith based counseling in a spiritually sensitive way can promote informed decisions which are congruent with patients' spiritual values. By considering their spiritual values with a counselor, patients may become more aware of what they do and do not want to have happen during their dying process.

Through thoughtful consideration of one's spiritual values, decisions about advanced directives and medical powers of attorney can be clarified. For instance, a patient's spiritual acceptance of the dying process may guide an advanced directive to refuse or accept further life-sustaining treatments, including food, water, and assisted respiration.

CAREGIVER CONFIDENCE

Finally, by providing turnkey care to the patient, the patient's family, and other concerned health care personnel, the chaplain / counselor can increase caregiver confidence that the patient's spiritual needs are being addressed throughout the dying process.

By helping the patient communicate to others his or her spiritual needs and desires we empower the patient to educate others about his or her wishes. When caregivers know that they are attending appropriately to the dying person's spiritual needs, caregivers are assured that the most existentially important aspects of the person's care are being satisfied.

This reassurance may increase caregiver confidence that "we did everything possible," and caregivers may be less likely to feel guilt during bereavement that important needs went unattended. Furthermore, attending to the spiritual needs of the dying individual may provide caregivers a profound sense of peace and significance about their care-giving; that they contributed meaningfully to the dying person's last days.

BEST PRACTICES

Elevate the patient's experience over routine. The notion that the individual care of a dying person should be elevated over the demands of day-to-day routine may seem axiomatic. The reality is that the urgent demands of paperwork, scheduling, meetings, competing needs of other patients, and even chaplain burn-out may significantly interfere with the quality of individual care.

The patient's experience should be elevated above routine by demonstrated commitment to attending to the patient's needs. This commitment is evidenced by providing adequate time for increasingly frail or ill clients to tell their stories, express their feelings, and put words to their fears.

The commitment is further evidenced by attention to detail, and personalized actions, such as sharing picture books with artistic patients, playing music to the patient's liking, and asking patients to share thoughts and memories about photograph albums, personal belongings, and other "linking objects".

Elevating the patient's experience over routine also entails appropriate attention to multicultural concerns, such as the patient's family traditions, cultural values, important religious rituals such as confession, fasting, creation of memorial altars, and anointing with oil. In addition to traditional talk therapy about spiritual issues, counselors may also consider using the senses of touch, hearing, taste, and smell in the co-creating (with the patient) of healing experiences or spiritual rituals.

For example, a patient may find the feel of silk on her skin to be helpful in achieving a meditative state of being or soothing instrumental music may help calm a patient after receiving distressing medical news. Incense, oils, candles, and perfumes can be used as long as the patient finds them helpful, and as long as such things do not interfere with medical treatment; particularly oxygen therapy.

Anything which lends meaning and significance to the patient's experience, and anything which provides a sense of comfort and support, should be considered for use in experiential therapies with dying clients.

Educate patients and caregivers. Both patients and caregivers require ongoing education about what to expect in the dying process. In addition to questions about physiological changes they can expect, patients and caregivers alike will benefit from preparation about psychological and emotional changes at the end of life, as well.

Such educational efforts on the counselor's part will help patients know what to expect. For example, patients and their caregivers may benefit from clear answers to specific questions such as, "Will I be abandoned?" "What will happen next?" "What is the actual dying process like?" and "How can I make the best use of my time now?"

BASIC SKILLS AND TECHNIQUES IN PROVIDING SPIRITUAL CARE

ASSESSMENT

All hospice team members are involved in spiritual assessment. All team members listen, utilize visual cues, and ask about patient and family spiritual/religious practices, frameworks, and needs. The chaplain or counselor often takes the lead.

The chaplain or counselor customarily conducts an in-depth assessment at the start of care and develops a plan of spiritual care directed by patient and family goals. The chaplain / counselor may prepare the patient for a question about spiritual needs by distinguishing between religion and spirituality, and asking the patient to think of his or her spirituality in terms of personal growth, meaning, values, and desire for whatever the patient's belief system holds after death.

A simple opening question might be, "Do you have any unfinished business, spiritually?" Other important questions to ask patients include:

- What do you hope for now, as you live with this diagnosis /condition/ unwanted news/ loss?
- What in all of this do you fear the most?
- What is left undone in your life?
- How are things going now for you and your family?
- What are you thinking about, in spiritual terms, as you consider your situation?
- Where do you turn for strength?

Questions like these open opportunities for discussions at deeper levels of meaning for the patient, and guide further treatment planning. As these questions are addressed with honor and compassion, patients may achieve an improved quality of life and inner peace as they consider their ultimate concerns in life and death.

Other methods for assessing spiritual needs of dying patients can be used, including individualized checklists, open-ended conversations, even discussion of patients' artwork, and personal narratives. As ongoing assessment yields new information, therapy and services can be adjusted accordingly, promoting continuity and quality of care on an individualized basis.

Ongoing assessment is crucial:

- As the patient's health status changes
- As new symptoms arise or are not relieved
- If the dying process is prolonged
- When death draws near

PROVIDING OPTIONS

“Some persons find that music, meditation, or prayer help relieve pain. Are any of these, something you would find helpful?”

EMPATHETIC PRESENCE

What is empathetic presence? “Don’t do something. Just sit there!”

Health care professionals are experts at solving problems, identifying goals, measuring outcomes; that means “fixing it” is their strength. The heart of spiritual care is empathetic presence, the opposite of fixing it. Empathetic presence helps people feel heard and not alone. Chaplains should be good at empathetic presence.

When patients and families are experiencing losses, despair, questions about the meaning of suffering, or a sense of abandonment by the divine, more than anything else they need to be heard and know they are not alone. It is essential to create an environment in which the person feels free to explore their concerns and openly express their feelings without feeling rejected or judged. Empathetic presence involves many skills and components:

- Active listening
- Relaxed yet engaged body posture
- Eye contact (when culturally appropriate)
- Reassuring touch (when culturally appropriate)
- Listening beyond or beneath the literal words said by a person to the deeper emotions, meaning, and needs

Empathetic presence may also involve a metaphorical “holding someone’s pain” as you are open-hearted, but do not become overwhelmed emotionally. It may also ask you to laugh, be joyous, and not focus on illness, pain, or dying.

In the face of comments such as “Why is God making me suffer so?” or “I just wish this were over, I can’t stand it anymore” empathetic presence might include:

- Acknowledging their suffering
- Saying you are sorry you don’t have the answer or solution
- Providing reassurance of your (or the team’s) ongoing care

WHAT DOES EMPATHETIC PRESENCE DO?

Empathetic presence is doing something. Fear, anxiety, despair, and even physical pain frequently diminish with the person feels heard, understood, and accepted for where they are in the process of coming to terms or coping with their terminal illness. Empathetic presence:

- Affirms personhood, self-worth, and dignity
- Decreases isolation
- Allows the person to find their own answers
- (For religious persons) mediates divine care

When empathetic presence is hard to sustain

- In the face of unrelieved and prolonged suffering
- When our own fears and insecurities are evoked
- When we identify too strongly with the patient or family
- Because of the age of the person
- Because of how they remind us of our own family or previous losses

When the patient or family is highly anxious and struggling with their own feelings of powerlessness, recall an experience from your own personal or professional life when you were unable to help someone feel better, take away their pain, or “fix” a problematic situation:

- How did you feel?
- How did you cope with these feelings?
- How did you respond to the person who was suffering?

Reflect for a moment:

- Are you a problem solver, seeking solutions and offering advice?
- What does it mean for you as a nurse, doctor, social worker, chaplain to be powerless?
- Do you feel a sense of failure in this situation?

NORMALIZATION OF PATIENT / FAMILY EXPERIENCE

WHAT IS NORMALIZATION?

Patients and families need to hear that what they are going through is “normal”. Although every person’s experience of illness, pain, spiritual suffering and dying/death is unique and needs to be validated as such, patients and families also benefit from hearing they are not “crazy”; that is, their feelings, fears, and even disease progression are “normal”.

Normalization of the experience builds trust in the palliative care/hospice team and conveys the message *we have seen this before and know how to help*.

- Normalization calms fears
- Normalization can diminish anxiety and fear
- Provides a “map” into this foreign territory

Normalization helps coping. It can sometimes help persons cope better with their own situation and connects them with others who are going through, or who have successfully gone through, a similar time of trial. Illustration by example is a good way to normalize.

A patient is highly anxious about their future ability to cope with symptoms and with the task of saying goodbye to loved ones;

Method one: One strategy of normalization would be to respond by saying, “Of course you are anxious.” or “It makes sense to me.”, “After all, you’ve never gone through this before and it is a lot to take on at once.”

Method two: Another strategy would be to tell the person that many of your patients were also anxious at first but, with a little assistance, these persons grew more trusting in how they would cope with the future.

WHEN NORMALIZATION CAN BE HELPFUL

- When the patient or family expresses wishes to hasten the dying process
- Frees persons to talk more about their underlying reasons or feelings by reducing judgment and guilt
- When the patient is actively dying
- Relieves concerns about terminal agitation, lack of appetite, inability to swallow, visions of deceased loved ones, and their own feelings of powerlessness and grief

USE OF RELIGION IN NORMALIZATION

Examples drawn from the specific religious literature or faith community of patients and families can help normalize and validate spiritual experiences. The example may help:

- Affirm their strength to cope
- Free them from having to be perfect
- Sustain their connection with something beyond themselves (e.g., human community, tradition, the divine)

APPROPRIATE / INAPPROPRIATE USE OF NORMALIZATION

Please exercise great care in using this technique. If used at the wrong time or in the wrong way persons may feel you are disregarding their feelings or trying to minimize their suffering.

LIFE REVIEW

Life review helps persons with concerns about:

- The purpose of their life
- Self-worth
- Need for forgiveness
- Closure with the past
- The progressive losses that accompany a life-limiting illness

Life review can help establish a person's "legacy". How they will live on in the future or how they wish to be remembered. In this way, it can also be helpful to bereaved families as it gives them a tangible "piece" of the deceased loved one. Life review can have special religious or spiritual significance for spiritual or religious persons; life review pays attention to their:

- Role in a community of faith
- Religious identity or self-understanding
- Relationship with the divine

For spiritual or religious persons, life review can also be a useful tool:

- To increase a sense of trust in the future (if God has seen them through hard times in the past)
- For spiritual growth work
- To resolve fears about the afterlife

EXPLORATION OF SOURCES OF HOPE & MEANING

GUIDELINES FOR EXPLORING MEANING

A larger framework of meaning can give patients and families a sense of purpose and ease suffering.

It is preferable for the patient or family to uncover and identify their own meaning rather than have this offered to them by others.

Religious or spiritual explanations for suffering, loss, and life-limiting disease are complex and often may not be comforting. Take care when exploring these issues with patients and follow rather than initiate and avoid intellectual debate.

GUIDELINES FOR EXPLORING HOPE

Sustaining hope in a cure or divine miracle, even if it seems unfounded, may be necessary for some persons. Refocusing on short term, achievable goals, when the patient and family are ready to do so, can defend against despair and help give a sense of purpose and control. Ask persons what they are hoping for during this time and, if they indicate they have no hope, allow for expression of these feelings. It may then be helpful to offer them other things to hope for such as:

- Comfort
- Strength for their family

- To be well-remembered
- To see the birth of a grandchild, etc.

AFFIRMATION OF SOURCES OF STRENGTH & COMFORT

Ask questions to assess sources of strength and comfort:

- “How have you coped with difficult times in the past?”
- “Where did you find strength?”
- “What gives you comfort?”
- “Is there anything you would find comforting now?”

Provide a “laundry list” if persons fail to come up with their own sources of strength and comfort: “Some persons turn to their family, their clergy, scripture, or humor for strength”. “Have you ever tried massage, meditation, soothing music, prayer, a walk in the woods, being held or a good cry?”

Explicitly name and affirm the qualities you observe as you work with patients and their families:

- Wisdom
- Knowledge
- Life experience
- Decision-making power
- Adaptability
- Graceful way of dealing with change or conflict
- Open communication
- Denial
- Particular philosophy of life

REFRAMING

At times, patients and families may benefit from seeing things from a different perspective. Reframing a situation can help persons cope; find meaning, and hope. A gentle way to introduce a different, more positive perspective is to begin with the words: “I wonder whether you have at times thought of this experience in different ways.” Or, draw upon examples or stories of other patients and families to open up the possibility of a different meaning or outcome situations where reframing is helpful.

Palliative care and hospice professionals frequently use this technique as we explain our medical care: “Although your doctor has told you nothing more can be done for your cancer, please rest assured there is a lot we can do to help you and your family during this difficult time.”

Other areas that are commonly reframed by palliative care and hospice include:

- Who needs to be present at the time of death
- The impact of a death on family members
- Role changes

In spiritual care, reframing draws upon the person's own belief system and religious tradition. At times it includes educating persons about aspects of their own tradition that may not occur to them or be unknown to them. As with other skills, it is important to use reframing thoughtfully so that difficult feelings such as anger, sadness, fear, etc., are not minimized.

DIVERSIONAL & LIFE-AFFIRMING ACTIVITIES

One of the most powerful ways to promote spiritual well-being is to connect persons with sources of life and joy, even in the midst of illness, suffering, and death.

The laugh of a child, a sunny day, the love of family, a political victory, even an exciting sports event can expand the world of ill persons and their families. Sometimes just taking the mind away from a problem, even for a short while, can be restorative.

As persons with terminal illness are able to “do” less and less, enjoying the simple pleasures of life may help restore a sense of purpose and personhood. For spiritual or religious persons, this may help reconnect them with that which is sacred, divine, or transcendent and reestablish a sense of gratitude and peace.

PRAYER, RITUALS & OBSERVANCE OF RELIGIOUS PRACTICES

Knowing, respecting, and helping sustain a person's religious rituals and practices is the responsibility of all hospice team members.

The degree to which you, as a team member, encourage the patient and family to utilize their spiritual or religious practices to find meaning, strength, and comfort depends on:

- Your knowledge of their spirituality
- Their comfort level in sharing this with you

Use open ended questions or suggestions:

“Is there anything from your spiritual practice that would be helpful to do now?” (Just before a difficult medical decision, for example.)

“In the past you have told me that prayer helps your pain. While we wait for the morphine to take effect, do you think it would help you to pray or would you rather sit quietly?”

PARTICIPATING IN RELIGIOUS PRACTICES

The degree to which you participate in the spiritual or religious practices of patients and families depends on both their and your own comfort level. Generally, it is best to let patients and families initiate the request for your participation. If you are unclear as to whether your presence is wanted, ask.

If you are uncomfortable with a request made of you to participate, let them know in ways that show your respect for their beliefs and needs in this area while acknowledging your own boundaries.

THE CHAPLAIN AND THE END OF LIFE

The chaplain's role in the interdisciplinary team: Awareness of one's own spiritual and emotional biases:

Perhaps more than any other disciplines in the health care setting, chaplains receive intensive preparation to help patients, families, and other staff deal with issues of loss, death, and dying. A Chaplain's role is broader than that of a clergy person who represents his or her own specific faith tradition.

While in some institutions patients may request a Muslim, Jewish, Protestant, or Roman Catholic chaplain, by and large chaplains serve persons from all religious traditions. Chaplains attend to specific religious needs such as:

- Ensuring that medical professionals respect religious beliefs and prohibitions
- Officiating at services in the hospital for religious holidays
- Offering prayers

Chaplains often work alongside the patient and family's own clergy, serving as a "translator" and patient/family advocate within a complex and often confusing medical environment. Though clergy are increasingly well-prepared to deal with end-of-life issues, many remain uncomfortable or unknowledgeable in this area.

Unlike most clergy, chaplains also provide spiritual (non-religious) care and counseling to patients and their families who are not affiliated with any specific religious tradition.

Because of their understanding of medical issues and expertise in helping patients and families identify their values and beliefs, chaplains are often called upon to assist with challenging medical decisions.

Many chaplains are members of a hospital's ethics committee and have received specialized training in ethical decisions at the end-of-life. The chaplain wears many hats and the chaplain is exceedingly ambiguous and flexible.

The chaplain's role is defined as much by the expectations of patients, families, and other health care providers as it is by the self-understanding of each chaplain. This role is often narrowed to a mere provider of sacraments or religious ritual. Education may be necessary so that patients and families receive all that the chaplain has to offer. At its richest, the role of the chaplain may include:

- Educator about religious and cultural frameworks and practices
- Translator and bridge-builder between the "culture" of medicine and that of patients/families
- Facilitator of communication
- Advocate for patient and family beliefs, religious and spiritual needs
- Mediator of the sacred, transcendent, divine
- Counselor, healer, agent of hope
- Ritual expert
- Calming presence in the face of crises
- Liaison to community clergy

Chaplains also have a role in providing spiritual care to staff. Chaplains who are on staff at hospitals and those who are members of a hospice or palliative care team provide both formal and informal spiritual and grief counseling to other health care providers. In this role, they may:

- Plan and officiate at memorial services
- Facilitate de-briefing sessions directed at the needs of other staff
- Make themselves available to help staff with questions about:
 - Meaning
 - Hope
 - Power/powerlessness
 - Ethical conflicts
 - Understanding of the divine
 - The afterlife
 - Other spiritual concerns that may arise in the course of providing care to terminally ill persons and their families

CONCLUSION

Counselors are wise to prepare for an increasing demand for spiritual care as clients age and confront death and dying. As the Baby Boom generation ages, approaches to client care in the dying process will change dramatically.

These approaches should include an attention to culturally sensitive interventions, actions to alleviate anxiety if the anxiety is creating difficulty for the patient, and on-going assessment of the patient's needs.

Death and dying are anxiety provoking topics for anyone, and counselors working with dying individuals need to remain alert to their own defenses in confronting their own death. Attention to the counselor's own death anxiety will help elevate the care of the dying individual above the routine, as well as promote self care and spiritual growth opportunities for the counselor.

NOTES

Module 5
Hospice Manual
Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. The provision of comprehensive spiritual care for dying individuals includes seven goals, name them.

2. Explain the effect that Baby Boomers are having on the field of spiritual counseling.

3. List the twelve reasons to ask about religious beliefs and practices.

4. Hospice chaplains provide care to patients, families and caregivers according to a set standard of practices and beliefs.
TRUE FALSE

MODULE 6: CHILDREN AND DEATH

Young children do occasionally express spontaneous insight into the finality of death, as when they encounter a dead animal or withered plant (Encyclopedia of Psychology, 2000). There are three stages of development of death related cognitions in children.

Stage one: present until age five, lacks appreciation of death as final and complete cessation. Separation is the theme most clearly comprehended by the youngest children.

Stage two: children think of death as final but not inevitable. A strong tendency to personify is noted in this stage.

Stage three: beginning at age nine or ten, is marked by comprehension of death as both final and inevitable. The prospect of personal mortality seems to be accepted. Anecdotal reports suggest that the child's discovery of death begins much earlier than most cognitive theorists seem prepared to accept.

The affective and cognitive development of children colors their understanding of death and their subsequent fears about dying. At the preschool, preoperational stage of cognitive development, death is seen as a temporary absence, incomplete and reversible, like departure or sleep.

Separation from the primary caretakers is the main fear of a preschooler. This fear surfaces as an increase in nightmares, more aggressive play, or concern about the deaths of others, rather than in direct discourse. Regression to more infantile behaviors signals increasing dependence on parents. Dying preschoolers need reassurance from their parents that they are loved, that they have done nothing wrong, that they are not responsible for their illness, and that they will not be abandoned.

School-aged children manifest concrete-operational thinking and recognize death as a final reality. However, they view death as something that happens to old people, not to them. Between the ages of 6 and 12 years, children have active fantasy lives of violence and aggression, often dominated by themes of death and killing. Death may be personified as a skeleton or bogeyman that takes people away. Dying school-aged children ask questions about their illness if encouraged to do so; however, if they receive cues that the subject is taboo, they may withdraw and participate less fully in their own care.

Many of us hesitate to talk about death, particularly with youngsters. But death is an inescapable fact of life which we must deal with, and so must our children. By talking to them about death, we may discover what they know and do not know; if they have misconceptions, fears, or worries. We can then help them by providing information, comfort, and understanding.

Long before we realize it, children become aware of death. They see dead birds, insects, and animals lying by the road. They may see death at least once a day on television. They hear about it in fairy tales and act it out in their play. Death is a part of everyday life, and children, at some level, are aware of it.

Mixed messages are confusing, and may deepen apprehensions and misunderstandings, and may leave children confused. Children look to adults for clues about how to behave in certain situations. It is usually easier to talk about death when we are less emotionally involved. Taking opportunities to talk to children about dead flowers, trees, insects, or birds may be helpful.

Some young children show intense curiosity about dead insects and animals. They may wish to examine them closely, or ask detailed questions about what happens physically to dead things. Although this interest may seem repulsive or morbid to us, it is a way of learning about death.

Children should not be made to feel guilty or embarrassed about their curiosity. Their interest may provide an opportunity to explain, for the first time, that all living things die and make room for new living things. If the death is violent, a murder or an assassination, it is probably a good idea to say something to reassure children about their safety.

Be open to their questions. Answer them truthfully and as completely as possible, given the age of the child. If you don't know the answer, just say so. If they want to attend the funeral, let them. If they want to view the body with the rest of the family, don't prevent them if they are mature enough to understand the inevitability and irreversibility of death.

Avoid euphemisms. Watch your terminology. Do not equate death with a journey or sleep, or the child may be afraid to go to bed. Do not say the person is "with Jesus" without further explanation. The child may hate Jesus for taking his/ her loved ones away from them. Make sure the child understands the difference between minor illness and fatal illness. The child may think they will die the next time they get a cold.

ADOLESCENTS

Capable of formal cognitive operations, adolescents understand that death is inevitable and final. Their major fears parallel those of all teenagers: loss of control, being imperfect, and being different. Concerns about body image, hair loss, or loss of bodily control may generate great resistance to continuing treatment. Alternating emotions of despair, rage, grief, bitterness, numbness, terror, and joy are common.

An adolescent's cognitive capacity to understand death may not translate into an understanding that their own personal death is possible. The potential for withdrawal or isolation is great because teenagers may equate parental support with loss of independence or may deny their fear of abandonment by actually repulsing friendly gestures. Teenagers must be part of the decision-making process surrounding their death. Many are capable of great courage, grace, and dignity in facing death.

ADULTS

Unlike children and teenagers, older adults often readily accept that their time has come. Although they may not be happy to die, they can be reconciled to it.

The final stage in the life cycle brings either a sense of integrity or despair. As elderly adults enter the last phase of their lives, they reflect on their time and how it has been lived.

Integrity of the self allows an individual to accept inevitable disease and death without fear of succumbing helplessly. However, if a person looks back on life as a series of missed opportunities or as filled with personal misfortunes, the sense is of bitter despair, a preoccupation with what might have been if only this or that had happened; then death is viewed with fear because it symbolizes emptiness and failure.

DEATH AND ITS CORRELATION

Fear and anxiety are among the most frequently used words to characterize orientations toward death throughout the life span. Investigations typically assume that death universally elicits anxiety. Where manifest fear is not present, defensive denial is inferred. Conscious fear of death is thought to occur only when there is a serious breakdown of the individual's defenses, as in extreme psychopathology.

One definition of "Death anxiety" is "the thoughts, fears, and emotions about that final event of living that we experience under more normal conditions of life". In other words, as people live their lives day to day, they suffer different degrees of anxiety about death.

The various factors psychologists have studied in attempting to measure death anxiety include:

- Age
- Environment
- Religious faith
- Ego integrity or a personal sense of fulfillment and/or self-worth.

A complicating aspect of studying death anxiety is that actually "measuring" anxiety as it relates to these variables has been difficult. The studies used in examining death anxiety do not experimentally manipulate the variables, thus limiting conclusions to correlations.

An additional confounding factor is the distinction between "death" and "dying." In other words, is the greater source of anxiety associated with death, itself, or the process of dying? In spite of these challenges, a number of researchers have reported conclusive findings relating to the impact of the variables noted above on death anxiety.

There is a relationship between death anxiety and age, ego integrity, gender, institutionalization, physical and psychological problems, and religiosity in older adults. It is reported that lower ego integrity, more physical problems, and more psychological problems are predictive of higher levels of death anxiety in elderly people.

An investigation on death anxiety among Chinese college students reported that younger as compared with older students and women as compared with men tended to be more death anxious.

Those with low levels of self-efficacy and external health control orientations were more likely to report a high level of death anxiety. There was a high level of negative correlation between death anxiety and age.

On the other hand, maturity was a better predictor of death anxiety than age and as psychosocial maturity and age increase, death anxiety decreases. Studies also concluded that women and less religious people reported to experience greater anxiety.

GENDER AND DEATH ANXIETY

Women report higher levels of death anxiety and they are more responsive and sensitive to the needs of people with life threatening conditions. This could be due to the fact that expressions of feelings, especially those of vulnerability, are encouraged in girls but discouraged in boys.

CHILDREN'S HOSPICE CARE

Nearly 10,000 children die of conditions such as cancer each year, fewer than 10% of the nation's 3,000 hospice programs provide end-of-life care for children, and "only a handful are specifically geared toward kids. " Children with terminal illnesses often spend the last days or weeks of their lives in a hospital, "hooked up to machines, as doctors try everything they can to head off the inevitable." By contrast, many adults with terminal conditions receive hospice care to help make them "as comfortable as possible, often at home," and to provide support to them and their families.

A children's hospice is a hospice specifically designed to help children who will not live to reach adulthood with the emotional and physical challenges they face, and also to provide respite care for their families.

A typical children's hospice service offers:

- Terminal Illness care within the child's home
- Bereavement counseling and support
- Information, advice and practical assistance
- 24 hour telephone support
- A system of contact or key workers who work with named children and families to ensure support is consistent and continued between visits
- Physiotherapy and many complementary therapies
- Music and play therapy
- Activities for siblings.

Children's hospice services work with families from all faiths, cultures and ethnic backgrounds and respect the importance of religious customs and cultural needs that are essential to the daily lives of each family. Many have a chaplain who is familiar with a variety of faiths and customs.

Each service is typically an independent charity which relies on public support to continue their work. This is an area where there is an ongoing need for expansion in the hospice care realm.

TALKING TO A CHILD ABOUT DEATH

The hospice staff should pay attention to whether a child is aware he/she is about to die, and in affirmative cases they should support parents who are reluctant to talk to their child about death.

"Pediatric oncologists can now say, based not only on their own experience but also with the support of hundreds of parents in the study, that no parents regret having spoken with their child about his/her death. If the child seemed to be aware of his/her impending death, which most of them are, then this communication is even more vital."

Caring for the sick child has affected parents most in the long term. Important factors can be the perception that the pain had not been sufficiently alleviated or that the moment of death was troublesome.

"If you are concerned about discussing death with your children, you're not alone." Many of us hesitate to talk about death, particularly with youngsters. But death is an inescapable fact of life. We must deal with it and so must the children; if we are to help them, we must let them know it is okay to talk about it.

By talking to children about death, we may discover what they know and do not know – if they have misconceptions, fears, or worries. We can then help them by providing needed information, comfort, and understanding. Talk does not solve all problems, but without talk we are even more limited in our ability to help.

What we say about death to children, or when we say it, will depend on their ages and experiences. It will also depend on our own experiences, beliefs, feelings, and the situations we find ourselves in; for each situation we face is somewhat different.

Some discussions about death may be stimulated by a news report or a television program and take place in a relatively unemotional atmosphere; other talks may result from family crises and be charged with emotions. When talking with children about death, regardless if it is their death or someone else's, these tips may help:

Warn children of grave illnesses.

If a family member or close friend is seriously ill, parents should discuss it with their children before death occurs. Then, if a death does occur, children will be prepared and the event will not be a complete surprise. Also, when there is a serious illness in the family, children can often sense that something unusual is taking place. The atmosphere of sadness in the home can be very frightening for children. It is, therefore, very important for parents to explain to their children what is going on and why they are sad and acting differently.

Talk to children soon after a death occurs.

It may be tempting to put off telling children about the death of a loved one simply to save them from sadness, but children must go through the grieving process just as adults must. The sooner children are informed, the sooner they can begin to deal with the loss. Speaking with children quickly also ensures that parents will be the ones discussing the death with their children, instead of someone else.

Define "dead" in clear and simple terms.

Parents should explain to their children what dead means. They should make sure their children know that the dead person won't be able to do any of the things he or she once did, like walk, talk, or breathe.

Avoid casual explanations.

Telling children that someone died because he was sick may lead them to believe that they themselves will also die when they are sick. It is very important, too, that parents not equate death with going to sleep. Telling children that "Grandma went to sleep and will not wake up." or something similar will likely cause children to be afraid to go to sleep for fear that they will never wake up.

Adults understand expressions like "passed away" and "gone to heaven," but these are very confusing expressions for children. For the most part, religious explanations are very confusing to children. Use words like "dead," "stopped working," and "wore out." These are simple words that help establish the fact that the body is biologically dead.

Fit the explanation to the children.

Parents should consider their children's level of development and what they already know about death before talking to their children about death. Parents should put their explanations into words that their children can understand and they should keep it simple. Parents should tell their children the facts and let them know they're available to answer any questions. Children's understanding about death depends on their level of development.

Two to six year olds

Children between the ages of two and six usually do not understand the finality of death. To them, death is something temporary or reversible. Many children this age may appear unaffected by the death of a loved one. This may be because they actually believe that the deceased person will return. Some children in this age range may take responsibility for death. They may believe that they did something to cause the death. It's important for parents to ask questions to determine feelings of responsibility and then to provide reassurance.

Six to nine year olds

Around the age of six most children begin to understand that death is a final thing; though this understanding is not complete. For example, children this age may see death as something that only happens to old people or to other people. Children may not be able to accept the fact that death happens to everyone.

Nine to twelve year olds

Some children in this age group may still take responsibility for the death of someone else. Understanding is increasing, and children in this age range can probably handle most of the information given to an adult. Parents should remember, though, that children under stress will often regress. Therefore, some children may not be able to handle all of the details.

Teens

By the time children reach the teenage years, they probably understand death and its finality as well as an adult. They usually realize the finality and irreversibility of death. Even though they have this understanding, they still need lots of support from parents and loved ones.

Be honest.

Children can sense when something is going on in their household. Even children as young as three are sensitive to these changes. They can also sense when someone is not telling them the whole truth. If children have been given an inadequate explanation and sense a cover up, they'll figure that they're dealing with something scary and unknown. They may even create a wild fantasy about what is happening that is much worse than the facts. Attempts by parents to avoid telling their children about a death usually backfire.

Encourage questions.

Parents should let their children know that they will try to answer any questions that their children may have and will answer them honestly. Parents should also let their children know that they're available to answer any questions that might come up later.

Include the children.

When someone close to the family dies, each member of the family is affected. Often, children are left out of the support network of relatives, neighbors, and friends. It is not a good idea to send children away to stay with a neighbor or friend at such a sad time. It is at such a time that children need the comfort and stability of their families and familiar surroundings. Parents should allow their children to grieve with the family and those who care about them instead of sending them away to grieve alone.

Try not to alter the daily routine.

Parents should try to keep life going in as normal a way as possible. They should try to maintain rules, and consistent mealtimes and bedtimes. Disruption of daily routines can be very upsetting to children, and it is thus best for parents to try to maintain some normalcy in the household at this difficult time. The more stable daily life remains for children, the easier things will be for them.

Allow children to grieve in their own way.

Mourning is the most natural response to death, and children need to mourn just as adults do. Parents should not attempt to prevent their children from feeling sad over the loss of a loved one. Instead, they should be reassuring and supportive towards their children. Sometimes children's reactions to death don't meet the parents' expectations. Some won't cry or show sorrow.

Others will ask what seem to be inappropriate questions. No two children grieve in the same way. Parents should, therefore, not expect their children to grieve in a certain way. It is not a good idea to insist that children display sorrow, or, on the other hand, that they act brave and dry their tears. Instead parents should encourage their children to express their feelings, whatever they are.

Don't hide your own grief.

Parents who are sad and grieving because of a death should not hide these feelings from their children. Instead, they should let their children know why they are sad, and they should reassure their children that they are not the cause of the sadness. Parents should not, on the other hand, turn to their children for emotional support. Children must be allowed to grieve without feeling responsible for supporting grieving parents.

Reassure.

When children confront death for the first time, they may be concerned about their own death. It is very important at such a time for parents to stress to their children that though no one knows for sure when they will die, they will probably not die for a very, very long time. Children may at this time also be afraid of the death of their parents.

Reassurance must be realistic, for parents also don't know for sure when they will die. Parents can let their children know that though no one knows for sure when they will die, they expect to be around for a long, long time.

Explain the rituals.

If children do decide to attend the funeral, parents should explain just what will happen at the funeral home, church or synagogue, the cemetery, and at home. They should explain how people will act and what the children will see and hear. Parents who expect to cry and express sadness themselves should tell their children this, too.

Designate a caretaker.

If parents cannot remain with their children at a funeral, a close relative or friend should be assigned the specific responsibility of sitting with and caring for them. This caretaker should be prepared to leave with the children if they find the service overwhelming. Very young children will probably not be able to sit still for an entire funeral service and should be allowed to go for a walk or to the bathroom with the caretaker.

A CHILD'S CONCEPT OF DEATH

Every child has their own unique concept of death. Past experiences with death for the terminally ill child, as well as, his/her age, emotional development, and surroundings are what most influence a child's own concept of death.

Cartoons, movies, television, video games, and even books are filled with images of death. The child with a terminal condition has most likely, previously experienced death by loss of a family member, friend, or pet.

An adult's misconceptions and fear about death are often transferred to the children. Treating death as a part of life is difficult, but may help alleviate some of the fear and confusion associated with it. Dealing with death must be done within the cultural beliefs and mores of the family.

DEVELOPMENTAL STAGES

Developmental age is a broad term used to describe the maturity of thought process development. Children go through a series of stages in their understanding of death. Children may be more or less mature in their thinking and processing information, than others, at a similar age.

INFANT

For an infant, death has no real concept. Infants do, however, react to separation from parents, painful procedures, and any alteration in their routine. An infant that is terminally ill will require as much care, physically and emotionally, to maintain a comfortable environment, as any age group.

Maintaining a consistent routine is important for the infant and his/her caregivers. Because infants cannot verbally communicate their needs, fear is often expressed by crying.

TODDLER

For the toddler, death has very little meaning. He may receive the most anxiety from the emotions of those around him. When a toddler's parents and loved ones are sad, depressed, scared, or angry, he senses these emotions and become upset or afraid.

The terms “death” or “forever” or “permanent” may not have real value to children of this age group. Even with previous experiences with death, the child may not understand the relationship between life and death. Death is not a permanent condition.

PRESCHOOL AGE

Preschool-aged children may begin to understand that death is something feared by adults. This age group may view death as temporary or reversible, and impersonal. Watching cartoon characters on television miraculously rise up whole again after having been crushed or blown apart tends to reinforce this notion. Death is often explained to this age group as “went to heaven.”

Most children in this age group do not understand that death is permanent, that everyone and every living thing will eventually die, and that dead things do not eat, sleep, or breathe. Death should not be explained as “sleep” to prevent the possible development of a sleep disorder.

Their experience with death is influenced by those around them. They may ask questions about “why?” and “how?” death occurs. The pre-school child may feel that his/her thoughts or actions have caused the death and/or sadness of those around. The pre-school child may have feelings of guilt and shame.

When a child in this age group becomes seriously ill, they may believe it is their punishment for something they did or thought about. They do not understand how their parents could not have protected them from this illness.

This idea may make the preschool-age sibling of a dying child to feel as if they are the cause of the illness and death. Young siblings of dying children need reassurance and comforting during this time period, as well.

SCHOOL AGE

Between the ages of five and nine, most school-aged children are developing a more realistic understanding of death. They are beginning to realize that death is final and that all living things die, but still they do not see death as personal. They harbor the idea that somehow they can escape through their own ingenuity and efforts. During this stage, children also tend to personify death. They may associate death with an angel, skeleton, or ghost, and some children have nightmares about them.

This age group is beginning to understand death as permanent, universal, and inevitable. They may be very curious about the physical process of death and what happens after a person dies. They may fear their own death because of uncertainty of what happens to them after they die. Fear of the unknown, loss of control, and separation from family and friends can be the school-aged child's main sources of anxiety and fear related to death.

ADOLESCENT

As with people of all ages, past experiences and emotional development greatly influence an adolescent's concept of death. From nine or ten through adolescence, children begin to comprehend fully that death is irreversible, universal, and inevitable; that all living things die, and that they too will die some day. They may or may not have had past experiences with death of a family member, friend, or pet. Some begin to work on developing philosophical views of life and death. Teenagers, especially, often become intrigued with seeking the meaning of life.

Most adolescents are beginning to establish their identity, independence, and relationship to peer groups. A predominant theme in adolescence is feelings of immortality or being exempt from death. Their realization of their own death threatens all of these objectives. Some youngsters

react to their fear of death by taking unnecessary chances with their lives. In confronting death, they are trying to overcome their fears by confirming their “control” over mortality.

Denial and defiant attitudes may suddenly change the personality of a teenager facing death. An adolescent may feel as if they no longer belong or fit in with their peers. In addition, they may feel as if they are unable to communicate with their parents.

Another important concept among adolescents is self-image. A terminal illness and/or the effects of treatment may cause many physical changes that they must endure. The adolescent may feel alone in their struggle, scared, and angry.

It is important for parents to realize that children of all ages respond to death in a unique way. Children need support and, in particular, someone who will listen to their thoughts, and provide reassurance to alleviate their fears.

Adolescents, similar to adults, may want to have their religious or cultural rituals observed.

ANTICIPATORY GRIEF

Anticipatory grief is similar to the normal process of mourning, but it occurs before the actual death (in anticipation of the death).

While mourning is usually discussed in regards to the family and loved ones of a dying person, anticipatory grief can be experienced by the dying child. Anticipatory grief occurs before death, often as a result of a terminal diagnosis or to a life-threatening illness, when death is a possibility. This grief has some common stages among people in the same situation; however, every individual and family is different and experiences grief, death, and illness in their own unique way.

PHASES OF ANTICIPATORY GRIEF

Grief and mourning do not have specified volumes or time restrictions. Each individual expresses his/her grief and bereavement in his/her own way and time. Anticipatory grief may include the following phases, though not exclusively in this order. Grief is often an expression which includes each of these phases or stages in multiple times, intensities, and orders.

Phase I

In this stage, an individual realizes that death is inevitable and there is no expectation for a cure. Sadness and depression are often associated with this first stage of grief.

Phase II

The next phase of anticipatory grief is concern for the dying person. Family members may regret arguments or disciplining the dying child. For the dying child, concern may be increased for

him/herself and his/her own fears of death, or because of the emotions expressed by loved ones around him/her.

Phase III

In this phase, the actual death may be “rehearsed.” The physical process of death and what may happen after death are concerns in this phase. Funeral arrangements and saying good-bye to loved ones may occur as a result of some anticipatory grieving.

Phase IV

In the last phase, loved ones may be imagining what their lives are going to be like without the person that is dying. Parents may be thinking about the unused toys left behind, missed proms and birthdays, or even what they are going to tell the child's teachers when school is missed. Siblings may wonder what it will be like to lose their brother or sister.

The person dying may think about life after death. The person dying may also try to imagine what it will be like for his/her loved ones to live without him/her.

NEEDS OF THE DYING CHILD

Meeting the physical needs of the dying child is aimed at providing as much comfort as possible. The change from curing to caring means providing comfort to the child with the least invasive procedures; while maintaining his/her privacy and dignity. A terminally ill child has many of the same needs as any seriously ill child.

The child with a terminal illness has the same need for love, emotional support, and normal activities as any person facing death. Love, respect, and dignity are all important factors in caring for a dying child. The following needs of the dying child should be considered:

A ROUTINE FOR SLEEP AND REST

Lack of sleep may be caused by the number of visitors, discomfort, fear of not waking up, restlessness, or day/night confusion. Keep a night light on and/or a bell or intercom available so your child will know where he/she is if awakened and confused. A clock is also helpful for older children who can tell time to help them orient themselves. Your child should have the ability to call upon someone, if needed.

Many people believe that if an adult or child has been diagnosed with a terminal illness, they must be in pain. This is not necessarily the case, and, when pain is present, it can be reduced or even prevented. Pain may occur as a result of the illness, or for other reasons. Children normally have headaches, general discomfort, pains, and muscle strains as part of being a child. Not every pain a child expresses is a result of the illness.

TIME TO BE A CHILD

Engage in age-appropriate activities for children, such as age-appropriate play. All of the child's time should not be consumed with "the illness."

LISTENING / COMMUNICATION

The child should have someone they can talk to about their fears, joys, angers, or to simply talk about the weather. Being alone at the time of death is a common fear for dying children. Listening to them is the most important way to help.

Accepting that the child does not want to talk about dying is also important; the parents' needs are often greater and they should seek out someone they can talk to. Just because "big" issues are not discussed, we should never underestimate the importance of a non-judgmental and caring presence.

INDEPENDENCE AND CONTROL

Independence and control need to be given to the dying teenager whenever possible. Many physical changes that occur before death can make the child very dependent for even simple tasks. Loss of control and depression may cause withdrawal. It is important to validate these feelings without forcing communication.

SPIRITUAL NEEDS

Spiritual and cultural needs should be respected and provided for. Rituals which allow the child and his/her family to remember, give thanks and express gratitude, trust God's presence in the experience for both the child who is dying and those who will grieve, and say goodbye are each ways to honor the transition from getting well to letting go or dying. What and how much to tell a child is dependent upon the culture and ethnic background of the family.

WISH FULFILLMENT

Some organizations provide funding for a "wish" for seriously and/or terminally ill children. If possible, help the child decide what they would most like to do before they die. A shopping spree, Disney World, a new computer, or meeting a famous star are examples of children's "wishes." If the child is able to actively participate, all measures should be provided for them. These wishes often create wonderful memories for families of children with a terminal illness.

PERMISSION FROM LOVED ONES TO DIE

Some children seem to require “permission” to die. Many children fear their death will hurt their parents and leaving them behind will make them very sad. It has been observed that children will cling to life through pain and suffering until they get “permission” from their parents to die. This has been described in the dying adult, as well. Sometimes, parents are not always the best persons to give this permission. Someone close to both the parents and the child may be more appropriate.

KNOWING THEY ARE NOT ALONE IN THE DYING PROCESS

The dying child most often wants reassurance that they will not die alone and that they will be missed. Parents and loved ones need to comfort the child and tell them that, when death occurs, they will be right at the bedside. This is often a difficult promise to keep, but every measure should be made to be holding or touching the child when he/she dies. The presence at death benefits both caregivers and the child.

LIMIT SETTING

Parents need to continue setting appropriate limits on a child's behavior and not let their guilt or grief inhibit their normal parenting, the consequence of which can be children becoming or feeling out of control.

COMMUNICATION BARRIERS

Many of us are inclined not to talk about things that upset us. We try to put a lid on our feelings and hope that saying nothing will be for the best. But not talking about something doesn't mean we aren't communicating. Children are great observers. They read messages on our faces and in the way we walk or hold our hands. We express ourselves by what we do, by what we say, and by what we do not say.

When we avoid talking about something that is obviously upsetting, children often hesitate to bring up the subject or ask questions about it. To a child, avoidance can be a message – “If Mommy and Daddy can't talk about it, it really must be bad, so I better not talk about it either.” In effect, instead of protecting our children by avoiding talk, we sometimes cause them more worry and also keep them from telling us how they feel.

On the other hand, it also isn't wise to confront children with information that they may not yet understand or want to know. As with any sensitive subject, we must seek a delicate balance that encourages children to communicate – a balance that lies somewhere between avoidance and confrontation, a balance that isn't easy to achieve. It involves:

- Trying to be sensitive to their desire to communicate when they're ready

- Trying not to put up barriers that may inhibit their attempts to communicate
- Offering them honest explanations when we are obviously upset
- Listening to and accepting their feelings
- Not putting off their questions by telling them they are too young
- Trying to find brief and simple answers that are appropriate to their questions; answers that they can understand and that do not overwhelm them with too many words.

Perhaps most difficult of all, it involves examining our own feelings and beliefs so that we can talk to them as naturally as possible when the opportunities arise.

AVOIDANCE

Even people who have strong beliefs may avoid talking about death. Once, death was an important and sacred part of family; loved ones died at home, surrounded by loved ones. Adults and children experienced death together, mourned together, and comforted each other.

Today death is lonelier. Most people die in hospitals and nursing homes where they receive the extensive nursing and medical care they need. Their loved ones have less opportunity to be with them and often miss sharing their last moments of life. The living become isolated from the dying; consequently, death has taken on added mystery and, for some, added fear.

Many people are beginning to recognize that treating death as a taboo does a disservice to both the dying and the living, adding to loneliness, anxiety, and stress for all. Efforts are underway to increase knowledge and communication about death as a means of overcoming the taboo. Scientists are studying the dying to help the living better understand how dying individuals experience their approaching deaths.

Children's perceptions also are being studied for a better understanding of how they think about death. Researchers have found that these factors seem to influence children's conception of death – their developmental stages and their experiences their environments, ethnic, religious, and cultural backgrounds, and their personal way of seeing things.

WHEN THERE ARE NO ANSWERS

When talking with children, many of us feel uncomfortable if we don't have all the answers. Young children, in particular, seem to expect parents to be all knowing, even about death. Death, the one certainty in life, is life's greatest uncertainty.

Coming to terms with death can be a lifelong process. We may find different answers at different stages of our lives, or we may always feel a sense of uncertainty and fear. If we have unresolved fears and questions, we may wonder how to provide comforting answers for our children.

While not all our answers may be comforting, we can share what we truly believe. Where we have doubts, an honest, "I just don't know the answer to that one," may be more comforting than

an explanation which we don't quite believe. Children usually sense our doubts. White lies, no matter how well intended, can create uneasiness and distrust.

Besides, sooner, or later, our children will learn that we are not all knowing, and maybe we can make that discovery easier for them if we calmly and matter-of-factly tell them we don't have all the answers. Our non-defensive and accepting attitude may help them feel better about not knowing everything also.

It may help to tell our children that different people believe different things and that not everyone believes as we do, e.g., some people believe in an afterlife; some do not. By indicating our acceptance and respect for others' beliefs, we may make it easier for our children to choose beliefs different from our own but more comforting to them.

THE DYING PROCESS

The body goes through many changes in the dying process. Knowing the common symptoms of impending death may help families and children be prepared for them when they occur. In some cases, the dying process can be very long. Understanding the physical and mental changes the body goes through as death occurs may help alleviate some fears and misconceptions about death. Always discuss any concerns or questions with your child's physician.

The following is a list of common symptoms that death is approaching. However, each child may experience symptoms differently. Symptoms may include:

- Changes in respirations may occur: Slow and fast respirations or long periods without a breath are common in the dying child.
- Moaning may occur with breaths and does not necessarily mean the child is in pain.
- Respiration may be noisy from secretions the child is unable to clear from his/her throat or lungs.
- Physical disfigurement may occur from a progressive tumor
- The skin color usually changes to pale, bluish, mottled, or blotchy. The changes occur due to a decrease in oxygen and the body's circulation slowing down.
- The child may suddenly become incontinent (unable to control bowel and/or urine elimination).
- Mental confusion or decreased alertness may occur just prior to death.
- Death has occurred when the child's heart is not beating and there are no signs of breathing.

Parents need to know that when a child dies at home in hospice care, it is not an emergency. (If paramedics are called, according to law, they must attempt to resuscitate the child, even if it is against the families' wishes.)

The family is provided as much time as needed before the child is removed from the home or hospital setting. This time is for the privacy of the family and loved ones and may include: holding, bathing, and/or dressing the child, or spiritual or cultural rituals. Even when death is anticipated, the family will be in shock and will be grieving.

The decision to pursue hospice care is a decision not to pursue aggressive treatment. In addition, hospice philosophy provides for the spiritual and cultural needs of the child and family. The goal of hospice care is to provide the terminally ill peace, comfort, and dignity.

THE INDIVIDUAL EXPERIENCE

While it can be helpful to know that children go through a series of stages in the way they perceive death, it is important to remember that, as in all growth processes, children develop at individual rates. It is equally important to keep in mind that all children experience life uniquely and have their own personal ways of expressing and handling feelings.

Some children ask questions about death as early as three years of age. Others may outwardly appear to be unconcerned about the death of a grandparent, but may react strongly to the death of a pet. Some may never mention death, but act out their fantasies in their play; they may pretend that a toy or pet is dying and express their feelings and thoughts in their make-believe game, or they may play “death games” with their friends, taking turns dying or developing elaborate funeral rituals.

No matter how children cope with death or express their feelings, they need sympathetic and nonjudgmental responses from adults. Careful listening and watching are important ways to learn how to respond appropriately to a child’s needs.

EXPLAINING DEATH TO A CHILD

Communicating with preschoolers or young school-age children about any subject can be challenging. They need brief and simple explanations. Long lectures or complicated responses to their questions will probably bore or confuse them and should be avoided. Using concrete and familiar examples may help.

One should explain death to a child so that death may be made more comprehensible by explaining it in terms of the absence of familiar life functions, when people die they do not breathe, eat, talk, think, or feel any more; when dogs die they do not bark or run anymore; dead flowers do not grow or bloom any more.

A child may ask questions immediately or may respond with thoughtful silence and come back at a later time to ask more questions. Each question deserves a simple and relevant answer. Checking to see if a child has understood what has been said is critical; youngsters sometimes confuse what they hear.

Also, children learn through repetition, and they may need to hear the same question answered over and over again. As time passes and children have new experiences, they will need further clarification and sharing of ideas and feelings.

It may take time for a child to understand fully the ramifications of death and its emotional implications. A child who knows that Uncle Ed has died may still ask why Aunt Susan is crying. The child needs an answer. "Aunt Susan is crying because she is sad that Uncle Ed has died. She misses him very much. We all feel sad when someone we care about dies."

There are also times when we have difficulty "hearing" what children are asking us. A question that may seem shockingly insensitive to an adult may be a child's request for reassurance. For instance, a question such as, "When will you die?" needs to be heard with the realization that the young child perceives death as temporary.

While the finality of death is not fully understood, a child may realize that death means separation, and separation from parents and the loss of care involved are frightening. Being cared for is a realistic and practical concern, and a child needs to be reassured. Possibly the best way to answer such a question is by asking a clarifying question in return: "Are you worried that I won't be here to take care of you?"

If that is the case, the reassuring and appropriate answer would be something like, "I don't expect to die for a long time. I expect to be here to take care of you as long as you need me, but if Mommy and Daddy did die, there are lots of people to take care of you. There's Aunt Ellen and Uncle John or Grandma."

Other problems can arise from children's misconceptions about death. Dr. R. Fulton, in Grollman's, *Explaining Death to Children*, points out that some children confuse death with sleep, particularly if they hear adults refer to death with one of the many euphemisms for sleep – "eternal rest", "rest in peace." As a result of the confusion, a child may become afraid of going to bed or of taking naps. Grandma went "to sleep" and hasn't gotten up yet. Maybe I won't wake up either.

Similarly, brief separations may begin to worry them if children are told that someone who has died "went away". Grandpa "went away" and hasn't come back yet. Maybe Mommy won't come back from the shops or from work. Therefore, it is important to avoid such words as "sleep", "rest", or "went away" when talking to a child about death.

Telling children that sickness was the cause of a death can also create problems, if the truth is not tempered with reassurance. Preschoolers cannot differentiate between temporary and fatal illness, and minor ailments may begin to cause them unnecessary concern. When talking to a child about someone who has died as a result of an illness, it might be helpful to explain that

only a very serious illness may cause death, and that although we all get sick sometimes, we usually get better again.

Another generalization we often make unthinkingly is relating death to old age. Statements such as, “Only old people die.” or, “Aunt Delores died because she was old.” can lead to distrust when a child eventually learns that young people die, too. It might be better to say something like, “Aunt Joyce lived a long time before she died. Most people live a long time, but some don’t. I expect you and I will.”

RELIGION AND DEATH

Religion is a prime source of strength and sustenance to many people when they are dealing with death. But if religion has not played an important role in a family’s life before death, a child may be confused or frightened by the sudden introduction of religious explanations or references.

Children tend to hear words literally, and religious explanations that may comfort an adult may unsettle a child. For example, the explanation, “Baby brother is with God now.” or “It is God’s will.” could be frightening rather than reassuring to the young child who may worry that God might decide to come and get her just as He did baby brother.

Also, mixed messages are confusing; deepening apprehensions and misunderstandings children may have about death. A statement such as, “Jimmy is happy now that he is in Heaven with the angels.” when coupled with obvious and intense grief, can leave them not knowing which to trust – what they see or what they hear.

They may wonder why everyone is so unhappy if Jimmy is happy. They need to hear something about the sadness we feel about losing Jimmy as we knew and experienced him, in addition to our expressions of religious faith.

Regardless of how strong or comforting religious beliefs may be, death means the loss of a living being, the absence of a physical presence. It is a time of sadness and mourning. It is important to help children accept the realities of death – the loss and the grief.

Attempts to protect children deny them opportunities to share their feelings and receive needed support. Sharing feelings helps. Sharing religious beliefs also helps if done with sensitivity to how children perceive and understand what is happening and what is being said. It is important to check with them to find out how they are hearing and seeing events around them.

THE UNEMOTIONAL OPPORTUNITY

It is usually easier to talk about death when we are less emotionally involved. Taking opportunities to talk to children about dead flowers, trees, insects, or birds may be helpful. Some young children show intense curiosity about dead insects and animals. They may wish to

examine them closely or they may ask detailed questions about what happens physically to dead things.

Although this interest may seem repulsive or morbid to us, it is a way of learning about death. Children should not be made to feel guilty or embarrassed about their curiosity. Their interest may provide an opportunity to explain for the first time that all living things die and in this way make room for new living things to take their place on earth.

This kind of answer may satisfy for the moment, or it may lead to questions about our own mortality. Honest, unemotional, and simple answers are called for. If we are talking to a very young child, we must remember that she can absorb only limited amounts of information at a time. She may listen seriously to our answers and then skip happily away saying, “Well, I’m never going to die.” We shouldn’t feel compelled to contradict her or think that our efforts have been wasted. We have made it easier for her to come back again when she needs more answers.

Other opportunities to discuss death with children occur when prominent people die and their deaths, funerals, and the public’s reaction receive a great deal of media coverage. When a death is newsworthy, children are bound to see something about it on television or hear it mentioned on the radio, in school, or in our conversations. In any case, it can rarely be ignored and, in fact, should not be. It is a natural time to give them needed information or to clarify any misconceptions they may have about death.

If the death is violent – a murder or assassination – it is probably a good idea to say something to reassure children about their safety. The media tends to play up violence under ordinary circumstances, and the violent death of a well-known or admired person may stimulate their fears or confirm distorted perceptions they may have about the dangers around them.

They may become worried that “bad” people or that the “bad feelings” in people cannot be controlled. They may need to hear that most people act responsibly and do not go around killing each other, even though everyone feels bad or angry at some time.

DEATH IN THE FAMILY – SOME CHILDREN’S REACTION

Studies have shown that when children experience the death of a close relative, such as a brother, sister, or parent, they often feel guilty. While most of us experience some guilt when we lose a loved one, young children in particular have difficulty understanding cause-and-effect relationships.

They think that in some way they caused the death; maybe their angry thoughts caused the person to die. Or they may view the death as a punishment. “Mommy died and left me because I was bad.”

Children may be helped to cope with guilt by reassurance that they have always been loved and still are. It also may help to explain the circumstances of the death. The notion that death is a form of punishment should never be reinforced.

The death of a close relative also arouses feelings of anger in both adults and children. We feel angry with the person who died for causing us so much pain and sorrow or for leaving us alone to cope with life. We feel angry at the doctors and nurses who could not save our loved one, and we feel angry at ourselves for being unable to prevent the death.

Children are more apt to express their angry feelings openly, especially when they've lost someone on whom they depended for love and care. It is difficult enough to hear anger directed toward the dead and even more so when it is expressed in what appears to be selfish concerns. But anger is part of grief, and we can help children by accepting their feelings and by not scolding them if they express anger or fear. Children need to be reassured that they will be cared for.

Some children turn their anger inward and become depressed, withdrawn, or develop physical symptoms. If this behavior persists over several months, professional help may be needed.

AFTER A CHILD'S DEATH

The death of a child is particularly tragic and may create special pitfalls for families. As parents, we must share our grief with our surviving children, for they too will have grief to share, but we must try not to burden them with unrealistic expectations and concerns. For example, there is a tendency to idealize the dead, and we must take care not to make comparisons that could lead to feelings of unworthiness and increase the guilt of surviving children.

It is also natural to deal with grief by turning our attention to the living. It is understandable that the loss of a child may lead to too much worry about the welfare of other children. However, we must resist any tendencies to overprotect them or smother their efforts to grow independent, and we must encourage them not to over-identify with or try to replace the lost child. Each child must feel worthy in her own right and must be free to live out her own life in her own way.

SHOULD CHILDREN VISIT THE DYING?

Most fatally ill people are hospitalized, and, as a rule, hospitals do not extend visiting privileges to children. But this is beginning to change as hospital staffs recognize the value that can be derived from having children visit. Whether or not a particular child should visit someone who is dying depends on the child, the patient, and the situation. A child who is old enough to understand what is happening probably should be permitted to visit someone who has played an important role in his life, providing that both he and the dying person wish it.

Under the right circumstances, contact with the dying can be useful to a youngster. It may diminish the mystery of death and help her develop more realistic ways of coping. It can open avenues of communication, reducing the loneliness often felt by both the living and the dying. The opportunity to bring a moment of happiness to a dying individual might help a child feel useful and less helpless.

If a child is to visit someone who is dying, she needs to be thoroughly prepared for what she will hear and see. The condition and appearance of the patient should be described, and any sickroom equipment she will see should be explained in advance. Also, it may be wise to remind her that although she is visiting someone who is dying, most hospital patients get well.

If visits are not feasible, telephone calls may be a handy substitute. The sound of a child's voice could be good medicine for a hospitalized relative, providing the child wishes to call and the patient is well enough to receive it. Under no circumstances should a child be coerced or made to feel guilty if he chooses not to call or visit the dying or if his contacts are brief.

SHOULD CHILDREN ATTEND FUNERALS?

Funerals serve a valuable function. Every society has some form of ceremony to help the living acknowledge, accept and cope with the loss of a loved one. Whether or not a particular child should be included, again, depends on the child and the situation. If the child is old enough to understand and wants to participate, being included may help him accept the reality of the death while in the supportive company of family and friends.

If a child is to attend a funeral, he should be prepared for what he will hear and see before, during, and after the services. He should be aware that on such a sad occasion people will be expressing their bereavement in various ways and that some will be crying. If possible, someone who is calm and can give serious consideration and answers to questions he may ask should accompany the child. If he prefers not to attend the funeral, he must not be coerced or made to feel guilty.

SENDING CHILDREN AWAY FROM HOME

The loss or impending loss of a close family member taxes our emotional and physical reserves to the extreme, and it becomes difficult to meet everyday responsibilities. It is even more difficult to care for youngsters, and sometimes we are tempted to send our children to visit relatives or friends until we can "pull ourselves together". Keeping children at a distance may also be a way to avoid talking to them about the death.

Careful consideration should be given before children are sent away, for this is when they most need the comfort of familiar surroundings and close contact with family members. They need time to adjust to the loss and, if feasible, should be prepared in advance for the death. Even young children who do not understand the full implications of death are aware that something serious is going on.

Sending them away may increase their fears about separation from their loved ones. Having familiar and caring people nearby before and after the death can reduce fear of abandonment or other stresses children may experience.

On the other hand, we do not want to keep our children under lock and key as a way of dealing with our own anxieties and needs. Our children should be given permission to play with friends or visit relatives if they wish to.

CHILDREN ALSO MOURN

Mourning is the recognition of a deeply felt loss and a process we all must go through before we are able to pick up the pieces and go on living fully and normally again. Mourning heals. By being open with our sorrow and tears, we show our children that it is all right to feel sad and to cry. The expression of grief should never be equated with weakness. Our sons as well as our daughters should be allowed to shed their tears and express their feelings if and when they need to.

A child may show little immediate grief, and we may think she is unaffected by the loss. Some mental health experts believe that children are not mature enough to work through a deeply felt loss until they are adolescents. Because of this, they say, children are apt to express their sadness on and off over a long period of time and often at unexpected moments. Other family members may find it painful to have old wounds probed again and again, but children need patience, understanding, and support to complete their “grief work”.

NEEDS OF A GRIEVING CHILD

This information must be clear and understandable at their development level.

- To be reassured that their basic needs will be met
- To be involved in planning for the funeral
- To be reassured when grieving by adults is intense
- Help with exploring fantasies about death, afterlife, and related issues
- To be able to have and express their own thoughts and behaviors, especially when different from significant adults
- To maintain age appropriate activities and interests
- To receive help with “magical thinking”
- To say good-bye to the deceased
- To memorialize the deceased

Help with anticipatory grief

- To be given information about the physical, emotional, and mental condition of the terminally ill person and given a choice of visiting or remaining away
- To be allowed to care for the dying person
- To participate in meaningful ways of saying goodbye
- To have schedules and boundaries as close to normal as possible
- To receive affection and be listened to

Signals for Attention from a Grieving Child

- Marked change in school performance
- Worry or anxiety manifested by refusing to go to school, go to sleep, or take part in age appropriate activities
- Not talking about the person or the death
- Physically avoiding mention of the deceased
- Frequent angry outbursts or anger expressed in destructive ways
- Hyperactive activities, fidgeting, constant movement beyond regular playing
- Persistent anxiety or phobias
- Accident proneness, possibly self-punishment or a call for attention
- Persistent nightmares or sleeping disorders
- Stealing, promiscuity, vandalism, illegal behavior
- Persistent disobedience or aggression (longer than six months) and violations of the rights of others.
- Opposition to authority figures.
- Frequent unexplainable temper tantrums.
- Social withdrawal
- Alcohol or other drug abuse.
- Inability to cope with problems and daily activities
- Many complaints of physical ailments
- Persistent depression accompanied by poor appetite, sleep difficulties, and thoughts of death.
- Long term absence of emotion
- Frequent panic attacks
- Persistent symptoms of the deceased.

Characteristics of Age Groups (to be used only as a general guide)

Infants - 2 Years Old:

- Will sense a loss
- Will pick up on grief of a parent or caretaker
- May change eating, sleeping, toilet habits

2-6 Years Old:

- Family is center of child's world
- Confident family will care for her needs
- Plays grown-up, imitates adults
- No understanding of time or death
- Cannot imagine life without mom or dad
- Picks up on nonverbal communication

- Thinks dead people continue to do things (eat, drink, go to the bathroom), but only in the sky
- Thinks if you walk on the grave the person feels it
- Magical thinking – you wish it, it happens (bring the dead back or wishing someone was dead)
- Death brings confusion, guilt (magically thought someone dead)
- Tendency to connect things which are not related

6-9 Years Old:

- Personifies death: A person or monster who takes you away; sometimes a violent thing.
- Still has magical thinking, yet begins to see death as final, but outside the realm of the child's realistic mind
- Fails to accept that death will happen to them – or to anyone (although begins to suspect that it will)
- Fears that death is something contagious
- Confusion of wording [soul/sole, dead body, live soul].
- Develops an interest in the causes of death (violence, old age, sickness).

9-12 Year Old:

- May see death as punishment for poor behavior
- Develops morality – strong sense of good and bad behavior
- Still some magical thinking
- Needs reassurance that wishes do not kill
- Begins an interest in biological factors of death
- Theorizes: People die to make room for new people
- Asks more about “what happened?”
- Concerns about rituals, burying
- Questions relationship changes caused by death, life changes
- Worries about who provides and cares for them
- May regress to an earlier stage
- Interested in spiritual aspects of death

Teenagers:

- View death as inevitable, universal, irreversible
- Cognitive skills developed
- Thinks like an adult
- Questions meaning of life if it ends in death
- Sees aging process leading to death
- Sees self as invincible – it will not happen to me
- Sees death as a natural enemy
- Need for adult guidance (grief process, coping skills)

- Needs someone to listen; to talk with
- May feel guilt, anger, even some responsibility for death that occurred
- Not sure how to handle own emotions (public and private)

IN SUMMARY

Communication about death, as with all communication, is easier when a child feels that she has our permission to talk about the subject and believes we are sincerely interested in her views and questions. Encourage her to communicate by listening attentively, respecting her views, and answering her questions honestly.

Every child is an individual. Communication about death depends on her age and her own experiences. If she is very young, she may view death as temporary, and she may be more concerned about separation from her loved ones than about death itself.

It is not always easy to “hear” what a child is really asking. Sometimes it may be necessary to respond to a question with a question in order to fully understand the child’s concern. A very young child can absorb only limited amounts of information. Answers need to be brief, simple, and repeated when necessary.

A child often feels guilty and angry when she loses a close family member. She needs reassurance that she has been, and will continue to be, loved and cared for.

A child may need to mourn a deeply felt loss on and off until she is in her adolescence. She needs support and understanding through this grief process and permission to show her feelings openly and freely.

Whether a child should visit the dying or attend a funeral depends on her age and ability to understand the situation, her relationship with the dying or dead person, and, most important, whether she wishes it. A child should never be coerced or made to feel guilty if she prefers not to be involved. If she is permitted to visit a dying person or attend a funeral, she should be prepared in advance for what she will hear and see.

NOTES

Module 6
Hospice Manual
Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. List five needs of a dying child and discuss how you would deal with each of them.

2. As a Chaplain, how would you deal with a 12- year old child who was terminally ill? Describe.

3. List the stages of development of death related cognitions in children.

MODULE 7: PREPARING FOR APPROACHING DEATH

Receiving a diagnosis that includes a probable life expectancy of “less than six months” is one of the worst moments imaginable...for everyone involved. No special “words of comfort” or philosophical discussion is going to make it “all better.” However, we can make the most of the time that is left and make the “quality of life” the best possible under the circumstances. The will to live is one of the strongest instincts within us, but all of us will die one day. Hospice offers a positive approach to coping with all the changes that accompany the dying process.

There are many factors that affect how such a diagnosis is received: the age of the patient, the “world view” of the patient and family, beliefs in God and an after-life or a belief that there is no “after-life,” the nature of the disease and its cause, and many others. Although some might imagine that everyone would agree with the statement “nobody wishes to die,” it is really not possible to make such an assumption and generalize.

Some who have lived a very long and full life may be ready to pass on. Those experiencing terrible pain may wish to escape it through death. In many cases, quality hospice care can control the pain and help the patient to be more comfortable.

There is no easy answer to “why” death comes to the very young or old when it does. Each of us must find our own answers, and those answers involve beliefs about the meaning of life, purpose in living, our relationships with those around us, our work, family and friends, and our goals.

Disbelief, shock and anger at hearing such a diagnosis is common, and it may take a long time for the initial shock and anger to subside, if it ever does. Disbelief and denial are natural and understandable responses to such a life-changing diagnosis. Time, however, has a way of making the reality of the disease known. Health and energy levels may decline while symptoms worsen, all of which make continued denial impossible. Grief and depression are common.

While to some, acceptance and peace seem to be unattainable far-off goals, others arrive at a state of peace and acceptance that comforts all around and allows for the expression of loving feelings among family and friends.

The proximity of death forces us to confront our own mortality, fears and beliefs. It also can help us overcome past hurts and grudges and reaffirm our love for one another. When death is imminent, we are also forced to make all sorts of decisions about the care given, interventions made, when to let go and what type of funeral arrangements will be made...all of which should be discussed with the patient to make sure his or her wishes are respected.

Hospice staff is available to listen and “be there” for the patient and family. Providing medications to control symptoms is only part of the hospice mission. Nurses, social workers and chaplains all work together to help the patient and family arrive at a peaceful resolution of the many complex issues which arise.

SPIRITUAL COUNSELING DURING HOSPICE CARE

Approaching death has a way of sobering all of us, so it is quite normal for many to re-evaluate their beliefs about life, religion and what happens after death. Hospice offers support at this time of questioning. Questioning why the illness occurred, where to find the strength to face all the challenges, how to face life without our loved one at our side...all of these questions and many more relentlessly confront us.

Hospice chaplains can help people work through the emotions and questions about a loved one's impending death, the meaning of life and other questions they may be wrestling with. Whatever a person's belief, hospice staff will be there to listen and provide support.

Hospices have ministers on staff (or on call) who are especially trained in dealing with the grief that arises when dealing with a terminal illness, and will assist people to find a spiritual counselor of any religious denomination.

Some families have not attended religious services for quite a while, yet feel a need for spiritual guidance at these times. Hospice chaplains can provide much insight and uplifting comfort. Even for those with no religious orientation, the chaplain is still available.

STAGES OF DYING

Being with the terminally ill can bring many positive things into our lives. It can, however, also bring on a feeling of oppressive despair that colors life in a tone of melancholy. Suddenly everything looks different. Priorities change. You reevaluate everything.

You see how short life is. You want to sleep all the time or you get no sleep at all. You lose 15 pounds or you gain 15 pounds. Make no mistake about it: holding the hand of someone as they die is a very, very difficult thing to do; even for the trained responder. The process wears many people down every day.

It is not surprising that the "deathwatch" often turns into an earnest, prayerful vigil for a swift end. The journey also brings a variety of stages and emotions for the dying person. Elizabeth Kubler-Ross, author of *On Death and Dying*, has carefully explained many of these. The stages of dying she focused on were denial, anger, bargaining, depression, and acceptance.

In my observation, it is important to remember that these stages do not always occur in every case. If they do all occur, they are in no way sequential or predictable. Some may be stuck on one stage for 90% of their time. More often, however, people go back and forth between a few of the stages.

As a loved one or caretaker, it's important that you do not judge a stage as good or bad. It is what it is: a stage, a moment. Focus on how you can support the person at whatever stage they find themselves and avoid tampering with that stage or their defense mechanisms. In one stage,

someone may feel a tremendous amount of anger towards the situation. In another stage, they may turn to religion and hope to strike a deal with God.

In addition to this, I have found that a significant number of people go through yet another stage in which they feel strengthened when they nurture their inner spirit. They do this in a variety of subtle activities: taking time to notice the beauty of nature, taking time for meditation, consciously appreciating the kindness of people in their lives, relating to people in a more genuine way, and speaking to loved ones and to God with deeper sincerity. These are all soulful expressions of a healthy, genuine, and flourishing spirituality. I call this stage “connecting.”

STAGES FOR THE CARETAKER

Most people aren't comfortable with end of life issues. In working on your own acceptance of these issues, your “helping someone through the process” and your “being-helped by the process” will begin to intersect. If you have someone in your life that is very ill now, you may think you are here to help them at the end of their life.

The truth is, this experience will do more for you (in helping you grow spiritually and emotionally), than you could ever do for anyone who is dying. I strongly believe the best way to work on spiritual growth is to help and be with someone through the dying process. Be there with your heart, and you will never be the same. Here are some stages you might go through as a caretaker.

FEAR

Often when someone begins helping a terminally ill person, they begin with a sense of insecurity. “Will I know what to say or do? Do I have the energy or time this will demand?”

THE HONEYMOON

After moving beyond fear and getting a few weeks under your belt, a feeling of confidence may fill your days. It feels good to do things for others. There is often a feeling of honest connection and closeness with the ill person. This often brings a strong feeling of self-esteem as you realize how good it is to help someone in such a situation.

THE ROLLER COASTER

Some days you get home and literally collapse from exhaustion, or perhaps the depression rubs off on you. By now, your bonding with the patient has solidified, and you may be sharing in their headaches, stress, and tension. This is when it's most important to focus on self-care.

LETTING GO

There comes a time when the caregiver needs to let go. After taking such an intense journey with another human being, it is understandable that this is a very difficult thing to do. Maintaining a high level of care for them, while at the same time being mindful of your own self-care, is very important. Take time to process your feelings by writing them out in a journal, talking with family and friends or joining a support group. More than ever, you need support at this time.

RELIEF & GUILT

Once the ill person has died it is common to have conflicting feelings. “I’m so relieved this is over.” is quickly followed by “What am I saying?!”... Which is then followed by, “I wish she was still here.” Or “I really miss him.” Everyone’s timetable for processing feelings of grief and loss is different. Don’t be too hard on yourself and try not to set a limit as to the amount of time it will take to heal. There is no “normal” number of days or weeks or years.

The spiritual needs of the dying concern professional counselors for two reasons. First, both long-term care of the dying and bereavement represent stressful and spiritually provocative situations for both the dying and their caregivers. Second, because the rate of death is expected to accelerate in the United States over the next 50 years, increasing numbers of people will experience these spiritually challenging and emotionally difficult situations (Smith, 2003).

This demographic, combined with an increasing interest in spirituality in the counseling literature, indicates that competence in understanding the spiritual needs of the dying will be helpful in providing competent counseling to an enlarging clientele.

EASE APPREHENSION

Chaplains can help dying ease their apprehension by helping them name their spiritual fears and concerns, by providing an opportunity to speak about them openly, and by extending validation and support.

Faith based counselors’ work with dying patients can provide a way of coming to terms with spiritual concerns through experiential methods such as guided imagery, artwork, poetry, religious ritual, breathing exercises, and progressive desensitization. This experiential process is limited only by imagination and physical abilities. Anything which the patient finds effective in alleviating anxiety can be considered.

EVALUATION OF SPIRITUAL NEEDS

Chaplains may prepare a patient for a question about spiritual needs by distinguishing between religion and spirituality, and asking the patient to think of his or her spirituality in terms of personal growth, meaning, values, and desire for whatever the belief system holds after death.

Some simple questions like, “What in all of this do you fear the most?”, “What is left undone in your life?”, “How are things going now for you and your family?”, and “What are you thinking about, in spiritual terms, as you consider your situation?”, open opportunities for discussions at deeper levels of meaning for the patient, and guide further treatment planning. They give the patient an opportunity to speak freely about things which may have been withheld for fear of reprisal or abandonment.

Five “most important” statements that dying people need to address: (a) I forgive you; (b) Please forgive me; (c) Thank you; (d) I love you; and (e) Good bye. Structuring conversations around these themes will help patients reach a sense of closure and preparedness for the dying process. As these questions are addressed with honor and compassion, patients may achieve an improved quality of life and inner peace as they consider their ultimate concerns in life and death.

CONCLUSION

Faith based counselors are wise to prepare for an increasing demand for spiritual care as patients age and confront death and dying. As the Baby Boom generation ages, approaches to patient care in the dying process will change dramatically.

These approaches should include an attention to culturally sensitive interventions, actions to alleviate anxiety if the anxiety is creating difficulty for the patient, and on-going assessment of the patient’s needs.

Death and dying are anxiety provoking topics for anyone and faith based counselors working with dying individuals need to remain alert to their own defenses in confronting their own death. Attention to the faith based counselor’s own death anxiety will help elevate the care of the dying individual above the routine as well as promote self care and spiritual growth opportunities for the counselor.

NOTES

Quiz

MODULE 8: BEREAVEMENT AND GRIEF

The grief process is a process of letting go and adjusting to a life that no longer includes the person who died. Grieving is often a difficult process; it is one full of challenges, setbacks, disorienting and sometimes painful emotions.

As mourners go through the process of grief they may feel as if they are traveling through a frightening, unfamiliar, and unpredictable landscape – a landscape where the hills are too steep to climb, and the valleys too dark to walk. However, with time and grief work, mourners can successfully negotiate their journey through grief. As they learn to integrate the new reality of a loved one's death, mourners begin to accommodate their grief. They begin to take up their lives once again.

We need to remember that each of us is changed by tragedy. Assuming our lives will continue just as they were before the death of a loved one is unrealistic. So is assuming that we ourselves will be just as we were before the death.

Both we, and our lives, are changed by the death of a loved one and by the grief we experience. However, as travelers who are making our way through the process of grief, we learn to find a new “normal” for our lives and to incorporate our grief into a new, normal way of being. Our journey through grief is a journey of becoming.

Our culture is a death denying one. We hide from death and deny the grief that follows. Because we feel uncomfortable around those who are dying, or those who are grieving the death of a loved one, we tend to avoid them.

Improvements in health care have contributed to our unfamiliarity with the grief process; increases in average length of life mean many young adults in our culture have not yet experienced the death of a close friend or family member. When someone we love actually dies, we're unprepared for the experience of grief.

Our lack of awareness about grief can make the grief process more difficult. We're frightened by the powerful feelings that sometimes engulf us. The normal symptoms of grief can make us think we are going crazy. One of the important goals of hospice bereavement care is the normalization of grief, which involves educating those in mourning about the grief process and reassuring them that the grief they are experiencing is a normal reaction to loss. They are not going crazy.

Each time we experience a loss, regardless how insignificant it may seem, we begin another journey through the process of grief. Sometimes the process is less painful because:

- The loss was not a significant one
- The loss was expected
- The loss seemed appropriate
- We had time to prepare for the loss

On other occasions a loss can be devastating. The grief process may seem like an endless walk through almost unbearable pain. For many, the death of a family member is among life's most painful losses. Depending on our relationship with the person who died and the way the death occurred, our grief may seem painful but bearable, or it may be so painful we feel completely overwhelmed.

The process of grief involves letting go of the person who died and learning to adjust to a new reality that no longer includes the loved one. When death is expected, friends and family members begin preparing for their loss during an initial phase called “anticipatory grief”.

As family members think about how their lives will be affected by their loved one's death, they anticipate the loss and begin to grieve. After the death occurs, family members continue the process of adjusting to a new environment which no longer contains the person they loved.

With the emotional support of friends and the hospice team, most family members can successfully negotiate their journey through the process of grief. However, the normal process of grief can sometimes go awry, triggering an episode of major depression or other serious emotional difficulty; then grief becomes complicated, and requires referral to a grief counselor or other specially trained professional.

The important thing to remember is that grief is not a contest. Each of us walks the journey in our own way. While most of us are able to accept our loss in our own way and at our own pace, there may be times when we need additional help.

COMMON REACTIONS TO A DEATH

Dr. Kubler-Ross' descriptions of denial, anger, bargaining, depression, and acceptance may or may not apply to the process a particular person experiences after the death of a loved one. The nature of the grief process varies depending on many factors.

As friends and family of the person whom has experienced the loss, we need to remember that they may or may not experience the reactions that Kubler-Ross describes. These reactions do not occur in any special order and may occur simultaneously.

Grieving individuals may be angry at the medical system one day, depressed the next, and then become angry again the next day, this time at the person who died. On the other hand, when a death is expected and “appropriate,” family members may feel sadness but little or no anger or depression.

We need to remember that each person experiences and processes grief differently. Some may feel more grief than others and some may be more open about their grieving. We need to respect the manner in which each person experiences grief, particularly when the process is different than expected.

The concept of grief as occurring in stages is fraught with difficulties. Sometimes we feel that we need to push the griever on to the next stage. We become concerned when the griever is angry for too long, or depression seems to last for weeks on end. Most of the time the best intervention for those who are grieving is supportive listening, and reassurance, as they experience the feelings of grief.

COMMON REACTIONS AND INTERVENTIONS

Common reactions are Shock, Denial/Disbelief, Anger and Hostility, Bargaining, What If's and If Only's; Depression and Acceptance/Reconciliation.

SHOCK

This is a common occurrence when a loved one dies, particularly when the death is sudden and unexpected.

Reaction: Inability to concentrate or think clearly, not being able to make decisions, feeling cold, weak, stunned, or numb; experiencing rapid swings in emotions.

Intervention: Provide a quiet, softened environment to reduce stimulation. Provide chairs or couches for the grieving to sit on. If they are restless, encourage them to walk or pace until they feel calmer. If they cry hysterically, let them. Uncontrolled crying usually only lasts ten or twenty minutes. Provide water, juices, and soft drinks, the less caffeine they ingest the better.

DENIAL / DISBELIEF

No matter if the death of the loved one was expected or not, there is a feeling of unreality when the death occurs.

Reaction: Denial and disbelief range from statements like, "I can't believe she's dead!" "It couldn't have been him!" "No, I won't let this happen!" to the hope that the person is only away temporarily, to more serious problems; such as refusing to recognize the body and even attempts to feed the corpse, or "mummifying" the deceased's room or clothes for years.

Intervention: Respect the need for denial. Resist the impulse to force the truth on anyone. Listen and be supportive. Shock, denial, and disbelief act as protection against something that can't yet be faced. Take your cues from the griever. If they say, "He's not coming back, is he?" provide gentle confirmation. If serious denial occurs, such as refusal to recognize the body, be patient and give the mourner more time to adjust. If strong denial persists, referral to a grief counselor may be necessary.

ANGER AND HOSTILITY

Anger and hostility are two of the most common reactions to grief. Whenever we feel helpless and out of control, we tend to get angry and blame someone else for our own painful feelings. When a loved one is dying, family members discover they are powerless to provide a cure.

Regardless how much they may want to, family members can't make everything OK. Becoming frustrated and angry, they displace their anger to whoever is closest.

Reaction: People will often feel shocked at how enraged they are with their loved ones for dying and leaving them alone, or furious with God for letting something so terrible happen. Then they will feel guilty for those feelings. Sometimes a physician is the target of their anger, and sometimes it is just the nearest person.

Intervention: We need to refrain from meeting anger with anger or hostility with hostility. If appropriate, validate the reasons for the anger. Remember that trying to make the family member see things more sensibly is not appropriate during a period of intense anger.

Try to remember that the expression of anger is a gift. **People often express their anger to those they trust the most.** Even in the midst of their most intense grief, the mourner is aware they might be abandoned by those who are unable to cope with their emotions. They may save their anger and hostility and express it to people who won't walk out on them. Just remember to not take it personally.

If anger becomes disruptive or abusive, setting limits is appropriate. If fighting occurs next to a bedside, they should be asked to leave and settle their differences elsewhere. If you are dealing with verbal abuse, you can call for a "time out" and explain you are there to listen, but they need to calm down before conversation can continue.

You may try suggesting a positive outlet for their anger, such as walking, jogging, cleaning the house, or writing down all their feeling on paper.

BARGAINING, GUILT, AND "IF-ONLYs"

Real or imagined guilt is a common reaction to grief. Family members realize they are unable to alter distressing family events that may have occurred in the past and are unable to retract decisions that did not turn out for the best. In any close relationship hurtful things are sometimes said. Frequently, in the rush of living, we don't get around to doing things we later wish we had. Or we do things we later wish we hadn't. Imperfections are normal. No relationship (and no person) is perfect.

Reaction: Family members are sometimes overwhelmed by thoughts of: "If only we had seen a different doctor, this wouldn't have happened." "If only we had gone to the doctor earlier, we would have caught the cancer earlier." "If only I had cooked more broccoli and less meat, the cancer wouldn't have occurred." etc, etc.

Bargaining during grief may include praying extra hard or trying to be extra good so the loved one would reappear. Sometimes those who are grieving attempt to stay so busy they won't have time to experience their grief. They make bargains by saying to themselves, "If I stay really busy, I won't have to feel so bad." Others may worry because they don't feel "bad enough" and then feel guilty about their lack of grief.

Intervention: Listen. Then help family members work through their irrational expectations of themselves. Normalize the guilty feelings by explaining to family members their feelings of guilt are normal. Instead, try to help them forgive themselves as they would forgive a friend. Suggest that they contact their spiritual/religious leader.

DEPRESSION

This can be the longest-lasting and most difficult reaction to grief because it involves utter despair and can seem endless.

Reaction: constant crying, fatigue, tremendous feelings of sadness, inability to concentrate, sighing, anxiety, irritability, and sleeplessness are all normal symptoms of the depression of grief.

Intervention: Reassure mourners that depression is a normal reaction and that depression comes and goes and eventually fades. Depression can be helpful because it allows the griever to experience the pain of the loss.

Offer support, empathy, reassurance, and try to avoid medication. Medication may relieve some symptoms of depression, but it does not resolve the grief. Although most mourners are able to negotiate the journey through grief without professional help, grief can trigger an episode of major depression or emotional difficulties.

Complicated grief is more likely to occur if: the death was violent and unexpected; multiple deaths occurred; or the mourner has a history of depression. When grief becomes complicated the appropriate intervention is referral to a grief counselor.

ACCEPTANCE / RECONCILIATION

This means the mourner understands both intellectually and emotionally that death has occurred. They understand that their loved one will no longer be physically present in their lives.

Reaction: Mourners are afraid of the word “acceptance” because they think that learning to accept the death means they are supposed to like the fact their loved one died. Mourners can also be afraid that accepting the death means they are supposed to forget the person who died.

Intervention: Reassure the mourner that grief is a process; a gradual decrease in the intensity of grief is normal. Also provide reassurance that reconciliation to a death does not mean forgetting a loved one. Beginning to focus on the future and taking up life once again is a sign of healing.

STAGES OF GRIEVING

The normal symptoms of grief don't feel normal at all. In fact, some of the most commonly experienced symptoms can be frightening. We need to remember that the stages of grief can co-exist, come and go, and rapidly replace one another.

PHYSICAL SENSATIONS

- Tightness in chest
- Over-sensitivity to noise
- Dry mouth
- Breathlessness
- Weakness
- Lack of energy
- Loss of sexual desire

THOUGHTS OR COGNITION

- Disbelief
- Confusion
- Preoccupation with the deceased
- Sensing deceased's presence
- Not wanting to let go

BEHAVIORS

- Absent-minded
- Social withdrawal
- Sleep disturbances
- Restlessness / over-activity
- Appetite disturbances
- Crying and sighing
- Visiting remembered places and the grave of the deceased.
- Calling out for the deceased
- Dreaming about the deceased

FEELINGS

- Sadness
- Anger
- Guilt or self-reproach
- Anxiety
- Loneliness
- Numbness
- Helplessness

- Shock
- Yearning
- Relief
- Rapid mood changes

DETERMINANT OF GRIEF

Understanding the determinants of grief can lead to early identification of family members and friends that have a potential to be high-risk grievers, or those that are likely to experience difficulties with the grief process.

1. Nature of the attachment: The most intense and difficult grief reactions often occur when the attachment between the bereaved and the deceased was very strong; when the deceased was needed to support the survivor's sense of self-worth and esteem; when the survivor was highly dependent on the deceased; or when the relationship was highly ambivalent.

2. Mode of death: The manner of death influences the grief response. A sudden death is often more difficult to grieve than one with advance warning. The natural death of an older person is usually not as difficult to grieve as the accidental death of a young child, a murder or a suicide. The bond between a child and grandparent may be stronger than the child's bond with a parent.

3. Historical antecedents: How the griever handled previous losses and how well those losses were resolved can help predict the griever's response to the current loss. A history of major depression or other emotional disorders may contribute to a more difficult period of mourning.

4. Personality variables: A person's ability to tolerate emotional pain and anxiety, and the ability to express feelings, can influence reactions to a death. Mourners with a history of adequate coping with other stresses, including other deaths, are more likely to be able to cope with the current death.

However, if previous losses included deaths of elderly friends or grandparents, the ability to cope with those deaths may not predict the ability to cope with the unexpected or violent death of a child.

Other personality variable affecting reactions to a death include introversion and extroversion. Extroverts want to express their grief to others. They find comfort in company and support groups. Introverts, on the other hand, tend to experience grief in a more solitary manner. They find solace in being alone or with a close friend. They may not talk about their grief for a while.

Some grievers experience their grief on a feeling level while other experiences their grief on a more cognitive or thinking level. Grievers with “feeling” personalities cry and want to be in touch with the emotions of grief. Those with more cognitive personalities tend to process grief in a more logical, orderly manner. “Thinkers” may not want to dwell on something that cannot be changed, such as the death of a loved one. Each of these ways of grieving, and many others, are appropriate ways to grieve.

5. Social Factors: The availability of support from family, friends, and the work-place can also influence our reactions to death. Coping with a death may be more difficult if the mourner has moved frequently, is estranged or geographically separated from other family members, or is not involved with a church or other supportive network.

Lack of cultural guidelines and rituals for grieving also affect our reactions to death. Cultures with established rituals and models for mourning, especially rituals that mark the time of mourning as a special phase, provide guidelines about what is normal during grief.

THE FOUR TASKS OF GRIEF

Although there is no right way to go through the process of grief, there are four tasks all griever must accomplish in order to successfully negotiate the grief process. The four tasks are the “work of grief” that each mourner must complete during the grief process. There is no set order in which the tasks must be accomplished. However, to begin the process griever must accept the reality of the loss, which is Task One.

Task One – Accepting the Reality of the Loss: Accepting the reality of the loss means working through the tendency to deny the death occurred and accepting, both intellectually and emotionally, the fact that the death occurred. Accepting the reality means acknowledging that the dead person will not be returning to this life.

Task Two – Experiencing the Pain of the Loss: Experiencing the pain of loss means giving up attempts to minimize grief and acknowledging the painful emotional reactions that accompany all loss, especially death. Since none of us likes to experience painful feelings, we're tempted to cut short the pain of grief, to get it over with and then get on with life.

Without actually meaning to, friends, other family members, and institutions also try to cut the process short. Places of employment want workers back and fully functional after three days. Caught in their own feelings of helplessness, friends encourage mourners to get on with their lives. However, in order to recover, mourners need to experience the painful feelings of grief.

Task Three – Adjusting to an Environment without the Deceased: Adjusting to a new environment that no longer includes the deceased is a painful process that takes time to accomplish. At first a mourner may not realize all the roles filled by a loved one. If the deceased were a spouse, the mourner may have lost a friend, lover, bill-payer, car washer, cook, or grocery shopper. In adjusting to the external environment, those who are grieving must also adjust to changes in their internal environment.

Mourners are accustomed to relating to the deceased in many ways, including emotionally and mentally. For example: when we notice a favorite store is having a sale or we hear a joke, we often think, “I can't wait to tell ____!” If the person we want to tell is the person who died, we experience waves of grief as we realize once again the person we are used to talking and sharing with is no longer physically present. Adjusting our thought patterns is part of adjusting to life without the person we love.

In the midst of the confusion and pain of grief, mourners may experience a great deal of resentment about having to learn tasks that used to be their partner's job. Learning how to work the washing machine, write checks, iron, manage a business, or arrange social occasions can seem overwhelming. However, moving from a state of helplessness to a state of responsibility for learning new skills is required to complete this task. With time, mourners often experience feelings for pride about their growing independence and new skills.

Task Four – Emotionally Relocating the Deceased and Moving on with Life: Emotionally relocating the deceased and moving on with life means the mourner begins to redirect his/her emotional energy from the person who is dead to those who are living, to satisfying hobbies, and/or to other activities. Successful relocation means taking up our lives again.

During the grieving process mourners may think the decision to become reconciled to grief means forgetting the person who died, so they struggle to keep their loved one in the present by putting their lives on hold. However, becoming reconciled to a loved one's death does not mean forgetting. Reconciliation means adjusting our relationship with the dead person from one of presence to one of memory. We begin to incorporate a painful new reality into our lives and make a decision to say “yes” to life.

It may be necessary to remind the mourner that feelings of sadness can resurface during anniversaries, birthdays, and holidays, or when other deaths or life crises are experienced. At such times our grief freshens; once again we feel sad, our throats tighten, and tears fall. However, as we heal we are able to experience our feelings and then let them go more easily. Instead of stabbing us in the heart, our grief becomes a dull ache.

A CAUTION ABOUT NOT GRIEVING

Until recently we thought controlling our feelings and hiding our grief was the right way to grieve. If we lost control of ourselves we were supposed to do it in the privacy of our own home, preferably behind closed doors. Now the pendulum has swung and we are supposed to show our feelings and grieve openly. In fact, friends, relatives, and sometimes mental health workers say things like, “If you don't grieve, you'll end up with cancer or high blood pressure...or in a psychiatric unit.” These kinds of statements are emotional threats and should never be spoken.

Currently there is no scientific proof that people who deny their grief will get cancer or go crazy. Some mourners grieve openly and in public. Others grieve quietly and in private. Some grieverers may be in such denial they are unable to face their loss at all, and that is their right.

While continued and pervasive denial prevents us from attaining resolution and may interfere with our lives in both physical and emotional ways, denial may be the only way some grieverers are able to go on. However, denying grief does not mean they will get cancer or go crazy.

YOU ARE NOT GOING CRAZY

Many people who have recently experienced the death of a loved one think they are going crazy, but they aren't. The common characteristics of normal grief include:

- Bodily distress of some type
- Preoccupation with the image of the deceased
- Guilt relating to the deceased or circumstances of the death
- Hostility
- Inability to function as before the death
- Development of traits of the deceased

Because grief is so painful we wonder if we're grieving in the "right way". Most grieving people experience one or more of the following:

- Feeling tightness in the throat or heaviness in the chest
- Having an empty feeling in their stomach and losing their appetite
- Feeling guilty at times and angry at others
- Feeling restless and looking for activity but finding it difficult to concentrate
- Feeling as though the loss isn't real
- Sensing the loved one's presence, finding themselves expecting the person to walk in the door at the usual time, hearing their voice, or seeing their face
- Wandering aimlessly and forgetting or not finishing things they've started around the house
- Having difficulty sleeping and dreaming of their loved one frequently
- Assuming mannerisms or traits of their loved one
- Experiencing an intense preoccupation with the life of the deceased
- Feeling as though they need to take care of the people around them by politely not talking about their feelings of loss
- Needing to tell and retell experiences of the loved ones' death
- Experiencing mood changes over the slightest things and crying at unexpected times
- Not wanting to go on living
- Feeling tired all the time

WHAT TO SAY

When caring for someone who has lost a loved one, there are some questions and phrases that can help them express their feelings. These include:

- I'm sorry for your loss.
- Tell me how you are feeling.
- Were you there when (name) died? What was that like for you?
- Tell me about (name), and your life with him/her.
- What special memories do you cherish?

Keep in mind that you don't have to say anything. Sometimes just your presence can be as comforting as verbal communication. Touching the bereaved on the hand, arm, shoulder or back is also acceptable, when appropriate, and shows them you care. Don't be afraid to cry with the bereaved, that also shows your compassion.

WHAT NOT TO SAY

Do be careful about what you say. There are certain clichés and phrases that should be avoided, and may not be true or appropriate. These include:

- I know just how you feel.
- Her/his death was for the best.
- It was God's will.
- He never gives us more than we can handle.
- Things will get better.
- Time heals all wounds.
- Now you have an angel in heaven watching over you.

THE LOSS OF HISTORY

Each family has its own special history and the shared bonds that are a part of that history. When a sibling dies, the bonds are shattered, and the history forever has a void that cannot be filled.

As they grow, children develop certain characteristics and talents. Brothers and sisters tend to complement each other by developing a balance of interests in different areas. However, surviving siblings will need to redefine their roles in the absence of this relationship.

COMPLICATED GRIEF

Losing a loved one is one of the most distressing and emotional experiences people face. But because death is such a common life experience, virtually everyone deals with grief at some point. Despite the emotional difficulty, most people experiencing normal grief and bereavement endure a period of sorrow, numbness, and even guilt and anger, followed by a gradual fading of these feelings, as they accept the loss and move forward.

For some people, though, this normal grief reaction becomes much more complicated, painful and debilitating, or what's known as complicated grief. In complicated grief, painful emotions are so long lasting and severe that people have trouble accepting the death and resuming their own lives.

Researchers are beginning to pay more attention to complicated grief because of the serious toll it can exact — possibly leading to depression and thoughts of suicide. Researchers have even

developed a new treatment that may help people with complicated grief come to terms with their loss and reclaim a sense of joy and peace.

SYMPTOMS

Mental health experts are still analyzing how complicated grief symptoms differ from those of normal grief or other bereavement reactions. During the first few months after a loss, many signs and symptoms of normal grief are the same as those of complicated grief.

However, while normal grief symptoms gradually start to fade within six months or so, those of complicated grief get worse or linger for months or even years. Complicated grief is like being in a chronic, heightened state of mourning.

Signs and symptoms of complicated grief can include:

- Bitterness about your loss
- Depression or deep sadness
- Difficulty moving on with life
- Extreme focus on the loss and reminders of the loved one
- Feeling that life holds no meaning or purpose
- Inability to enjoy life
- Intense longing or pining for the deceased
- Irritability or agitation
- Lack of trust in others
- Numbness or detachment
- Preoccupation with your sorrow
- Problems accepting the death
- Trouble carrying out normal routines
- Withdrawing from social activities

Historically, people who didn't follow the steps in order or who became stuck at one of these stages were thought to be in an unhealthy grieving pattern. Today, though, most grief experts don't embrace this theory, instead believing that while grief is an evolution, most people don't go through organized stages.

RISK FACTORS

Complicated grief is considered relatively uncommon. Because research about complicated grief is evolving, it's difficult to know how many people are affected. Some estimates suggest that as few as 6 percent or as many as 20 percent of bereaved people develop complicated grief.

While it's not known specifically what causes complicated grief, researchers continue to learn more about the factors that may increase the risk of developing it. These risk factors may include:

- An unexpected or violent death
- Being unprepared for the death
- Childhood separation anxiety
- Close or dependent relationship to the deceased person
- In the case of a child's death, the number of remaining children
- Lack of a support system or friendships
- Lack of resilience or adaptability to life changes
- Suicide of a loved one
- Traumatic childhood experiences, such as abuse or neglect

WHEN TO SEEK MEDICAL ADVICE

It's normal to experience grief after a significant loss. Most people who experience normal or uncomplicated grief can move forward eventually with support from family and friends. But, if it's been several months or more since the loss and a person's emotions remain so intense or debilitating that they have trouble going about their normal routine, some sort of professional intervention should be considered.

Specifically, a person may benefit from professional help if they:

- Believe that they did something wrong or could have prevented the death
- Can focus on little else but their loved one's death
- Feel as if life isn't worth living
- Have lost their sense of purpose in life
- Have persistent pining or longing for the deceased person
- Have thoughts of guilt or self-blame
- Wish they had died along with their loved one

At times, people with complicated grief may consider suicide.

NOTE: If you're **considering suicide**, reach out to someone as soon as possible. The best choice is to **call 911** or your local emergency services number.

TESTS AND DIAGNOSIS

Complicated grief isn't yet recognized by mental health providers as an actual disorder. However, there's growing consensus that it should be. And even though it's not an official disorder, a person may still be diagnosed with complicated grief.

To help diagnose complicated grief, mental health providers perform a thorough psychological evaluation. They ask many questions about the events surrounding the loss of a loved one; the patient's mood, thoughts and behavior; the patient's lifestyle and social situation, and sleeping

and eating patterns. The patient may also fill out psychological questionnaires and have a physical exam to check for any other health problems that may be causing or contributing to the symptoms. Because bereavement also can lead to other disorders, such as depression or post-traumatic stress disorder, the patient may be evaluated for those conditions, as well.

Generally, to be diagnosed with a certain mental health disorder, someone must meet specific criteria spelled out in the Diagnostic and Statistical Manual of Mental Disorders (DSM). This manual is published by the American Psychiatric Association and is used by mental health providers to diagnose mental conditions and by insurance companies to reimburse for treatment.

Different diagnostic criteria have been proposed. One proposal that has gotten support includes these criteria:

- A belief that the future won't be fulfilling
- A feeling that life is now meaningless
- Difficulty moving forward with life
- Excessive bitterness or anger related to the death
- Feeling emotionally numb or detached from others
- Inability to trust others after the death
- Increased agitation or jumpiness
- Intense pining or longing for the deceased that occurs daily or is distressing or disruptive
- Trouble accepting the death

For diagnosis of complicated grief, these symptoms must last at least six months and cause impairment or disruption in a patient's ability to function in daily life, such as at work or in social engagements.

COMPLICATIONS

Complicated grief can affect a person physically, mentally and socially. Without appropriate treatment, these complications can include:

- Depression
- Suicidal thoughts or behaviors
- Increased risk of heart disease, cancer and high blood pressure
- Anxiety
- Long-term impairment in daily living
- Post-traumatic stress disorder
- Substance abuse
- Smoking or nicotine use

TREATMENT

Complicated grief treatment hasn't been standardized because mental health providers are still learning about the condition. Research studies testing various types of treatment have had mixed results. That isn't to say that treatment isn't helpful. More study is needed to help determine which treatment options may be best for complicated grief.

PSYCHOTHERAPY

Some studies have shown big benefits from treating complicated grief with a newly developed type of psychotherapy called complicated grief treatment, or complicated grief therapy. This form of psychotherapy, which borrows from cognitive behavior therapy and trauma therapy, is comprehensive and sometimes intense. A person may learn about such topics as grief reactions, complicated grief symptoms, adjusting to the loss and redefining life's goals.

This therapy also includes holding imagined conversations with the deceased loved one and retelling the circumstances of the death, perhaps several times, to help the patient become less distressed by images and thoughts of their loved one. Although some people find this therapy painful, others find it ultimately rewarding and freeing after what may have been years of chronic mourning.

Other forms of therapy, such as interpersonal therapy or psychodynamic psychotherapy, also may be effective. Therapy can help a person explore and process emotions, improve coping skills and reduce feelings of blame and guilt.

MEDICATIONS

There's little solid research on the use of psychiatric medications to treat complicated grief. However, some research has shown benefits from using antidepressants in the class of selective serotonin reuptake inhibitors (SSRIs) to reduce complicated grief symptoms.

PREVENTION

It's not clear how to prevent complicated grief with any certainty. Some studies suggest that participating in a brief course of counseling or psychotherapy soon after a loss may help, especially for those at increased risk of developing complicated grief. In addition, caregivers providing end-of-life care for a loved one may benefit from counseling and support to help prepare for death and its emotional aftermath.

Through early counseling, a person can explore emotions surrounding the loss and learn healthy coping skills. This may help prevent negative beliefs about the loss from gaining such strong holds that they're difficult to overcome. People who, themselves, may be at risk of suicide following a loved one's suicide may especially benefit from grief counseling or other treatment.

Finding support from family, friendships, group therapy or social support groups after a loss can promote healthy grieving. One can also take steps to improve resilience skills to help cope with hardships and loss.

COPING AND SUPPORT

Although it's important to get professional treatment for complicated grief, a person can take steps on their own to cope, including:

Stick to the treatment plan. Take medications as directed and attend therapy appointments as scheduled.

Exercise regularly. Physical exercise helps relieve depression, stress and anxiety and can redirect the mind to the activity at hand.

Take care of yourself. Get enough rest, eat a balanced diet and take time to relax. Don't turn to alcohol or un-prescribed drugs for relief.

Reach out to the faith community. Those who follow religious practices or traditions may gain comfort from rituals or guidance from a spiritual leader.

Practice stress management. Learn how to better manage stress. Unmanaged stress can lead to depression, overeating, or other unhealthy thoughts and behaviors.

Socialize. Stay connected with people you enjoy being around. They can offer support, a shoulder to cry on or a joke to give you a little boost.

Plan ahead, for special dates or anniversaries. Holidays, anniversaries and special occasions can trigger painful reminders of a loved one. Find new ways to celebrate, or acknowledge a deceased loved one, that provide comfort and hope.

Learn new skills. For those who were highly dependent on a loved one, perhaps to handle the cooking or finances, learning to master those tasks can be helpful for coping. Friends and family can provide guidance when necessary as can community resources.

Join a support group. A person may not be ready to join a support group immediately after a loss, but over time may find shared experiences comforting and may form meaningful new relationships.

SEVEN CHOICES OF GRIEF

While there is no set progression through grief, there is a process we follow, with choices along the way. Elizabeth Harper Neeld, Ph.D., has identified *seven choices* as the steps in the grief process.

Impact

The impact is the initial crisis after the event. This phase may last days or weeks after learning of the death of your loved one. This phase can be characterized by reactions – specifically physical, behavioral, emotional, and cognitive.

Second Crisis

The second crisis occurs any time during the first few months. The numbness from impact has worn off and the bereaved may feel more pain than they believed was possible. It is important to experience the pain and not try to hide it or “be strong” for others. Friends and family members may have returned to their lives at this point, so looking into community resources may be ideal.

Observation

This phase is a time to reminisce and re-experience the deceased, according to author Theresa A. Rando. Many old memories will be recalled; many people are surprised by the amount of everyday moments they recall.

The Turn

In a downward swing after experiencing their loss, the bereaved starts to adjust to a life without the deceased. Hopefully, the reinvesting in life begins and the widow and/or family makes the turn upward.

Reconstruction and Working Through

The bereaved has relinquished attachments to old roles, relationships, and to the world of the deceased. Instead, a new relationship with the departed – a relationship of memory – is developed. This is the time that the bereaved starts to take action and reinvest themselves in a world without their loved one.

Integration

Finally, in integration, the bereaved are able to think of the deceased person without pain. There is always a sense of sadness, but it lacks the wrenching quality it previously had.

There are times or life events that may rekindle grief reactions in the bereaved such as special dates (birthdays, anniversaries), special rituals (weddings, graduations) and new crises.

PREPARING TO HELP

You have a good friend who has just experienced the death of a loved one. Perhaps you know instinctively what to do, but maybe you do not. Perhaps you have never lost a person you love. Maybe you haven't even been to a funeral. This is not unusual.

Many people do not have occasion to attend a funeral until late in adulthood. Maybe your friend is of a different culture and you are not sure what rituals or customs would be correct. Use the following as a guide in preparing for the day when a friend has lost a loved one.

Review a personal grief experience. Think back to your childhood and to a time you experienced the death of a loved one or even a pet. Remember what it was like for you. Who died? How did you feel? What was helpful? What was not helpful? The more you understand your personal experience with death and grief, the more comfortable you can be in reaching out to a friend.

Become familiar with the process of grief. There are many books in libraries and bookstores that are written about grief and loss. Find one and read it to understand better what your friend may be experiencing.

Use the correct language. If someone has died, say the word “died” instead of euphemisms, such as “passed.”

Pace yourself. Helping a bereaved friend is hard work, and your friend will need you for months to come. Think realistically about how much time you can give without denying your own family important time together. In the beginning, your friend will need you more, with less assistance required as he or she becomes more independent.

WHEN DEATH OCCURS

PRACTICAL HELP

There is so much to do after a death, but ordinary, practical help is needed first. Make phone calls and answer the telephone, keeping a record of messages. Make sure the house is presentable, and help to clean it, if necessary. Keep track of food and other gifts for thank you notes, and note which bowls belong to whom for later return.

Help with the children: Children have special needs and may be ignored during this time. Talk to them about what they are feeling and thinking.

Run errands: There are usually dozens of errands that need to be done. Ask for a list or help prepare one. Perform the ones you can and delegate the others.

Pick up out-of-town friends and relatives: Offer to make trips to the airport or bus station to pick up those who are arriving to attend the funeral. Help find convenient and affordable lodging, or make arrangements with neighbors or friends to offer spare bedrooms.

Encourage the person to take time out to rest: Grief is exhausting, but if a bereaved person is running on adrenaline, he or she may not be aware of the body's need to take a break.

Help with funeral arrangements: At the time of death, families are tempted to spend huge amounts of money for the funeral, but their decisions may not be well thought through. Offer to go to the funeral home, but have a discussion about price beforehand.

Spending thousands of dollars is not necessary for a nice funeral: Help make the funeral more personal by incorporating the deceased's personality into a service of celebration of that person's life. If there are children present, suggest a special funeral service that would be shorter and more informal than the adult service.

EMOTIONAL HELP

Think about how much time you can give: Before committing yourself, determine how much time you can give without creating problems in your own family. Visits over a longer period of time are more important than many visits during the first week, when other friends and relatives are still available. With the departure of these people, the bereaved may feel isolated. Now is the time for you to start your visits, which may vary in length.

Learn good communication skills: It is easy to do all of the talking, especially if you are anxious. Try not to fill every pause with chatter unless you have something important to say. Communication isn't always with words; use your eyes, as well. How does the person look? Is she restless? Has her posture changed?

Be a good listener: Listening is the most important gift you can offer a grieving person. Every time the bereaved tells his or her story, the reality of what has happened will sink in. The loss must become real in order for a person to move through the process of grief. As a listener, encourage the person to talk and express feelings.

Help the bereaved organize his or her day: People tend to feel overwhelmed when a loved has died because there is so much to do. Help organize urgent tasks, and those that can wait until a later time. Develop and post a list that can be checked off when tasks are completed.

Help with thank-you notes: With an outpouring of support from family, friends and co-workers, this task may seem monumental. A person will have certain people to whom he or she will want to write personal notes. However, there are many thank-you notes that can be signed on behalf of the bereaved. That intimidating pile of cards can decrease quickly with your help.

Watch the children and their emotional needs: Grief is so encompassing that children may be forgotten or ignored. See to their needs.

Share memories: Sharing memories is so healing. Bereaved people love to hear stories about their loved ones.

Watch for depression: It is normal for bereaved people to experience some depression, and reminiscing usually helps break it up. However, if you feel concerned about the degree of depression a person may be exhibiting, suggest seeking professional help.

Identify local resources: Find further resources for the bereaved, such as support groups, books, or therapists who specialize in grief. You can locate resources by calling your local hospice or mental health center.

Take care of yourself: Helping the bereaved is hard work. Don't forget to take care of yourself. Find someone you can talk to. Check with your family and remain aware of their needs. Take time for yourself to do something special, such as taking long walks, reading a book, watching a favorite TV program, enjoying a quiet bath or listening to some of your favorite music. Take care of yourself. You will be needed you for a long time.

AVOID VACUOUS PLATITUDES

People sometimes worry that they will say the wrong thing. The following are some things to avoid:

“I know how you feel.” One can never know how another may feel. Instead, you could ask the person to tell you how he or she feels.

“It's part of God's plan.” This phrase can make people angry and they often respond with, “What plan? Nobody told me about any plan.”

“Look at what you have to be thankful for.” They know they have things to be thankful for, but right now they are not important.

“Call if you need anything.” They aren't going to call. It is much better to offer something concrete, such as: “I have two free hours and I want to come over and vacuum your house or work on your lawn.”

“He's in a better place now.” The bereaved may or may not believe this. Keep your beliefs to yourself unless asked.

“This is behind you now; it's time to get on with your life!” Sometimes the bereaved are resistant to getting on with because they feel this means “forgetting” their loved one. In addition, moving on is easier said than done. Grief has a mind of its own and works at its own pace.

Statements that begin with “You should” or “You will:” These statements are too directive. Instead you could begin your comments with: “Have you thought about. . .” or “You might. . .”

Making decisions for the bereaved: You can help the bereaved make decisions by exploring the pros and cons of what or what not to do. If you make a decision and it ends up being a bad one, the bereaved may be very angry with you. Moreover, you may be reinforcing dependence on you.

Discouraging expressions of grief: It is best to “encourage” the bereaved to express grief. If the bereaved begins to cry, do not change the subject, rather give a hug, make a pot of coffee or find the tissue.

Promoting your own values and beliefs: It's okay to share yours as long as you are not trying to convince the bereaved that your way is better. Listen as the bereaved talks about his or her values and beliefs.

Encouraging dependence: The bereaved may tend to lean on you too much. It is better to gently encourage independence with your support and guidance.

MOURING THE DEATH OF A SPOUSE

Anytime your spouse dies your world changes. You are in mourning, feeling grief and sorrow at the loss. You may feel numb, shocked, and fearful. You may feel guilty for being the one who is still alive.

If your spouse died in a nursing home, you may wish that you had been able to care for him or her at home. At some point, you may even feel angry at your spouse for leaving you. All these feelings are normal. There are no rules about how you should feel. There is no right or wrong way to mourn.

When you grieve, you can feel both physical and emotional pain. People who are grieving often cry easily and can have:

- trouble sleeping
- little interest in food
- problems with concentration
- a hard time making decisions

If you are grieving, in addition to dealing with feelings of loss, you may also need to put your own life back together. This can be hard work. During this time, you may be surprised by some of your feelings, but they are a part of mourning.

Some people may feel better sooner than they expect. Others may take longer. As time passes, you may still miss your spouse, but for most people the intense pain will lessen. There will be good and bad days. You will know that you are feeling better when the good days begin to outnumber the bad.

For some people, mourning can go on so long that it becomes unhealthy. This can be a sign of serious depression and anxiety. If your sadness stays with you and keeps you from carrying on with your day-to-day life, talk to your doctor.

WHAT CAN YOU DO?

At the start of your grieving, you may find that taking care of details and keeping busy helps. For a while, family and friends may be around. But there comes a time when you will have to face your new life alone.

Here are some ideas to keep in mind:

Take care of yourself. Grief can be hard on your health. Try to eat right, exercise, and get enough sleep. Avoid bad habits, such as drinking too much alcohol or smoking, which can put your health at risk. Be sure to take your medicines as your doctor ordered. Remember to see the doctor for your usual visits.

Talk to caring friends. Let your family and friends know when you want to talk about your husband or wife. It may help to be with people who let you say what you're feeling.

Join a grief support group. Sometimes it helps to talk to people who are also grieving. Check with hospitals, religious groups, and local government agencies to find out about support groups.

Try not to make any major changes right away. It's a good idea to wait for a while before making big decisions like moving or changing jobs.

See your doctor. If you're having trouble taking care of your everyday activities, like getting dressed or fixing meals, talk to your doctor.

Don't think you have to handle your grief alone. Sometimes short-term talk therapy with a counselor can help.

Remember your children are grieving, too. You may find that your relationship with your children has changed. It will take time for the whole family to adjust to life without your spouse.

Remember – mourning takes time. It's common to have rollercoaster emotions for a while.

Do Men and Women Feel the Same Way?

Andrew, age 73, felt like the wind had been knocked out of him when his wife died. He began sleeping all day and staying up at night watching TV. Meals were mostly snacks like cookies and chips. He knew it wasn't healthy, but he didn't know what to do. Across town, Alice woke up in a panic. It had been 5 weeks since Jeff, her husband of 41 years, died. She cared for him during his long illness. How was she going to cope with the loneliness?

Men and women share many of the same feelings when their spouse dies. Both may deal with the pain of loss and both may worry about the future. But because many couples divide their household chores, there can also be differences. For example, one person may pay bills, clean house, and handle car repairs. The other person may cook meals, file income taxes, and mow the lawn. This splitting up of jobs works well until there is one person who has to do it all.

Some men are at a loss when it comes to doing household chores. But these jobs can be learned over time. Men are sometimes surprised when they're widowed. For those men who are both widowed and retired, grief may cause depression.

Facing the future without a husband can be scary for some women. Many have never lived alone. Some women will worry about money. Women who have never paid bills or balanced a checkbook will need to learn about managing money.

Women may also worry about feeling safe. It's a good idea to make sure there are working locks on the doors and windows. If you need help, ask your family or friends. You'll need to get in the habit of taking care of your house and car. It takes time, but it can be done.

Taking Charge of Your Life

After years of being part of a couple, it can be upsetting to be alone. Many people find it helps to have things to do every day. Write down your weekly plans. You might:

- Be part of a chorus.
- Consider adopting a pet.
- Go to the library to check out books.
- Join a bowling league or a sewing group.
- Join a community exercise class or a senior swim group.
- Meet with old friends.
- Offer to watch your grandchildren or a neighbor's child.
- Sign up for bingo or bridge at a nearby recreation center.
- Take a walk with a friend.
- Think about a part-time job.
- Volunteer at a local school as a tutor or playground aide.

Some widowed people lose interest in cooking and eating. It may help to have a noon meal at a senior center, cafeteria, or with friends. When home, some people find that turning on a radio or TV during meals helps with loneliness.

STAY BUSY

When you feel stronger, you may need to think about:

- Writing a new will.

- Looking into a durable power of attorney for legal matters and a power of attorney for health care in case you are unable to make your own medical decisions.
- Putting any joint assets (such as a house or car) in your name.
- Checking on your health insurance as well as your current life, car, and homeowner's insurance.
- Signing up for Medicare by your 65th birthday.
- Paying state and federal taxes.

When you are ready, go through your husband's or wife's clothes and other personal items. It may be hard to give away these belongings. Instead of parting with everything at once, you might make three piles: one to keep, one to give away, and one “not sure.” Ask your children to help. Think about setting aside items like clothing, a watch, favorite book, or picture to give to your children or grandchildren as personal reminders of your spouse.

Having a social life can be hard. It may be scary to think about going to parties alone. It can be hard to think about coming home alone. It may be even harder to think about dating. Some people miss the feeling of closeness and affection that marriage brings.

Here are some things to remember:

- Go slowly. There's no rush.
- It's okay to make the first move when it comes to planning things to do.
- Try group activities. Invite friends for a pot luck dinner or go to a senior center.
- With married friends, think about informal outings like walks or movies rather than “couples” events that remind you of the past.
- Find an activity you like. You may have fun and meet people who like to do the same thing.
- Remember that friendship can come in many forms.

Don't Forget

- Take care of yourself.
- Get help from your family or professionals if you need it.
- Be open to new experiences.
- Don't feel guilty if you laugh at a joke or enjoy a visit with a friend.

You are adjusting to life without your spouse.

THE NEWLY WIDOWED

Losing a loved one, whether through unexpected or anticipated circumstances, is always traumatic. This is especially true with the death of a spouse. It is one of life's most profound losses.

The transition from wife to widow, husband to widower, is a very real, painful, and personal phenomenon. The trauma of trying to adjust to this new identity while being besieged with a multitude of urgent questions and decisions can be overwhelming.

Here are several things to remember when faced with the death of your spouse. While they may seem simple, they are very important points to remember:

Give yourself permission to mourn.

Men and women both need to give themselves permission to mourn. Postponing a confrontation with your feelings by filling each day with frantic activity will only delay and compound the grief reaction. Denying your grief can be helpful in separating yourself from the pain. But, the agony is still there and it will stay there until you acknowledge it.

Be aware that you may experience a range of emotions.

Your reactions to death may cover a wide and confusing range of emotions (such as shock, numbness, anger, pain, and yearning). It may help to think of grief as clusters of reactions or fluid phases that overlap one another. Grief does not proceed in an orderly fashion any more than life itself does.

With effort, you can and you must overcome your grief.

One of the myths about mourning is that it has an ending point, that if you just wait long enough, it suddenly stops hurting. It doesn't. It requires work. More than time, bereavement takes effort to heal. Mourning is a natural and personal process that only you can pace. It cannot be rushed and it cannot happen without your participation.

When needed, find the strength to take action.

As a newly widowed person, there may be urgent financial and legal decisions you must make following the death of your spouse. You have just suffered an emotionally devastating event and the last thing you want to deal with is money matters. But money does matter, now and for your future, so try to do the best you can. Postpone, however, any decisions that can be put off until you feel better emotionally.

Work to tame your fears.

When the first impact of death wears off, you may feel you are losing control. This is a normal part of the grieving process.

Unlike mental illness, the strong feelings suffered during grief gradually and permanently disappear. Because you may experience a feeling of temporary instability, it's important to remember that you have the ability to cope. This is a time when much of your adjustment to widowhood takes place.

In your own time, in your own way, you can say goodbye.

The present, with all its pain and sorrow, is the only reality you have. Memories are very important, but they cannot be used as a shield against the present. At some point in your grieving, you will be ready to try to say goodbye.

Stress can wreak havoc on your health.

The effect of grief on our health is just beginning to be measured. While guarding your health can be among the least of your concerns during the throes of grief, you must work toward maintaining your health as soon as you feel able. This means beginning some form of regular exercise, getting proper nutrition, and reporting physical complaints to your doctor.

If interested, consider employment, continuing education or volunteer opportunities that match your needs and interests.

Entering the job market after a long absence, or for the first time, can be one of the most challenging tasks that widowed persons encounter. If interested, look for ways to enhance, capitalize and build on the skills you've developed over the years. Don't be afraid to ask about employment opportunities whenever and wherever you can.

There are also volunteer opportunities that are meaningful and personally fulfilling in your community, which you may want to consider.

PARENTS WHO ARE NOW CHILDLESS

The death of any child overwhelms that child's parents, regardless of the cause of death or the age of the child. Parental grief is intense, long-lasting, and complex. Many believe that this grief, desolation, and pain exceed all other bereavement experiences a person may encounter in a lifetime. Bereaved parents are completely bewildered and find it difficult just to function.

When a parent faces the death of an only child, the only surviving child, or all children, bereavement is compounded by additional issues that ultimately must be resolved if healing is to occur.

Suddenly, you are childless. There is a new and total silence in your life. Your world feels abruptly empty; you imagine you are alone. These feelings may last for many months, even years, as you move through early bereavement.

These thoughts and feelings are normal. When a child dies, the lack of surviving children is an additional heartbreaking issue that initially deepens your pain as you seek a way to share your love.

Although these early months and years may seem endless, you can slowly move toward a positive resolution of your grief. Although you may remain childless, you can seek and embrace

healing. Your life will not be what you had planned before the death of your child or children, but living can still hold beauty, joy, peace, and meaning.

ARE YOU STILL A PARENT?

Because you do not have surviving children, you may find your parental identity suddenly questioned because you no longer have living children to parent. Ultimately, however, you will realize that once you have been a parent, you are forever a parent.

The memories of your child or children and the love you shared with them live on and are always a part of you. During early bereavement, memories can be extremely painful. Over the years, your memories, while bittersweet at times, will become sources of comfort and even joy.

THE JOURNEY THROUGH GRIEF

The journey from early bereavement toward your “new normal” is hard work, especially when you feel that a part of you died with your child or children. The work of grief involves dealing with unfamiliar emotions and pain.

Do not postpone your grief or feel you have to “get over” the death of your child. Sorrow will accompany you on this journey, but do not fear or reject it, as it is natural and normal. For a long time, your emotions will resemble a wild roller-coaster ride.

You may find that tears respect neither time nor place. Remember that tears release emotional pain and help to prevent physical ailments caused or exacerbated by stress. On the other hand, although you will need time to genuinely enjoy yourself again, you need not feel guilty about experiencing the relief of feeling or expressing joy. You will find that laughter and tears are equally important in your grief journey.

There are no prescribed limits on the period of bereavement; healing can take a considerable amount of time. You may wish to share with others who have experienced the pain of a child’s death. Other bereaved parents have felt similar pain and emptiness; you can cry and grieve with them, knowing that they understand much of what you feel.

You need not feel alone. With others, you can approach a new future to replace the one you have lost. Healing can take a considerable time and there are no prescribed limits.

HOW MANY CHILDREN DO YOU HAVE?

Bereaved parents usually find it difficult to answer the question “How many children do you have?” Some wish to honor their children’s memories by acknowledging their lives and answering, “I had one child,” or “I had two children.” Others are more comfortable answering,

“None.” You may find that your answer changes based on the circumstances. The key is to be prepared to say what you want to say at the moment.

As you mourn your loss, family members and friends might urge you to concentrate on what you have left. Since you may feel you have nothing left, you may resent these urgings. At these times, it is important to remember that your family and friends want to alleviate your suffering.

They want to see you whole once more, not only because they love you, but also because your pain reflects their own fears of death, both for their loved ones and for themselves. Those who have not experienced the death of a child cannot imagine the emotional pain you feel. Explain that your feelings are both real and appropriate.

MEMORIES

Do not be afraid to keep the memories of your child alive. You may find joy in commemorating your child’s life by sharing it with others. Mementos of the past can be made a part of today and the future. You may find it comforting to wear an article of clothing or a favorite piece of jewelry that your child once wore. You might take bits and pieces that were a part of your child’s life and make a collage or a quilt to hang in your home. Even a favorite toy on a shelf is a way to ensure that your child’s memory is a tangible presence in your daily life.

REINVESTMENT

One of the most demanding challenges you will face is to refocus your life. The purpose and the thought of a lonely life, possibly without subsequent children and their families can be frightening.

Gradually your life will begin to inch forward. How to reinvest is difficult to decide as you reevaluate your current life and resolve to move forward from your loss. But as you do, the grief intensity often lessens, and you may find yourself determined to live the remainder of your life in a way that will honor or commemorate the life of your child or children.

Many parents strive to find and support ways to help prevent children from dying in the same manner. Others may work within the community to further areas of interest once shown by their children. There are countless ways to reinvest in life and these may include using your parenting skills in new ways; such as becoming foster parents or volunteering in youth organizations.

There are other constructive ways to honor the memories of sons or daughters. Many parents establish memorial funds, create scholarships, donate books to libraries, plant trees, or help other more newly bereaved parents. For many, such acts of love help to keep the memories of their children alive and vibrant.

A GUIDE TO GRIEF

Grief is a normal response to loss. It can be the loss of a home, job, marriage or a loved one. Often the most painful loss is the death of a person you love, whether from a long illness or from an accident or an act of violence.

This guide will help you understand the grief you and others may feel after a death, whether sudden or anticipated. We hope this guide will help you realize that these feelings are not unusual and things can get better. You are not alone.

THE GRIEVING PROCESS

Grief is painful and at times the pain seems unbearable. It is a combination of many emotions that come and go, sometimes without warning. Grieving is the period during which we actively experience these emotions. How long, and how difficult, the grieving period is depends on the relationship with the person who dies, the circumstances of the death, and the situation of the survivors. The length of time people grieve can be weeks, months, and even years. One thing is certain: grief does not follow a timetable, but it does ease over time.

Because grief is so painful, some people try to “get over” a loss by denying the pain. Studies show that when people don’t deal with the emotions of grief, the pain does not go away. It remains with them, and can turn up in unrecognizable and sometimes destructive ways. Understanding the emotions of grief and its feeling and symptoms are important steps in healing and in helping others who may be grieving.

THE FEELINGS AND SYMPTOMS OF GRIEF

Experts describe the process of grieving and the emotions of grief in various ways. The most commonly described reactions are: shock, denial, anger, guilt, depression, acceptance, and growth. Some people experience the grieving process in this order. Most often, a person feels several of these emotions at the same time, perhaps in different degrees.

SHOCK

If the death comes suddenly, as in an accident or murder, shock is often the first response people feel. Even if the death is anticipated, there may be disbelief at its finality. A person may be numb, or, like a robot, be able to go through the motions of life while actually feeling little. At the same time, physical symptoms such as confusion and loss of appetite are common.

DENIAL

Shock and denial are nature’s way of softening the immediate blow of death. Denial can follow soon after the initial shock. People may know their loved one has died, but some part of them can’t yet accept the reality of the death. It is not uncommon to fantasize that the deceased will

walk through the door, as if nothing has happened. Some people leave bedrooms unchanged or make future plans as if the loved one will participate, just as in the past.

ANGER

Anger is normal. It may be directed at the deceased for leaving and causing a sense of abandonment, or at the doctors and nurses who did not do enough, or at a murderer who killed without remorse. People of faith may feel anger at God, for allowing so much pain and anguish. Anger may also be directed at oneself for not saving the life of the loved one. It can be a mild feeling or a raging irrational emotion. It can test one's faith in religion or even in the goodness of life.

GUILT

Few survivors escape some feeling of guilt and regret. "I should have done more" are words that haunt many people. Were angry words exchanged? Most people are very creative in finding reasons for guilt. So many things could have been done differently "if only I had known."

SADNESS

Sadness is the most inevitable emotion of grief. It is normal to feel abandoned, alone and afraid. After the shock and denial have passed and the anger has been exhausted, sadness and even hopelessness may set in. A person may have little energy to do even the simplest daily chores. Crying episodes may seem endless.

ACCEPTANCE

Time alone will not heal grief. Acknowledging the loss and experiencing the pain may free the survivor from a yearning to return to the past. Accepting life without the lost loved one may give way to a new perspective about the future. Acceptance does not mean forgetting, but rather using the memories to create a new life without the loved one. Hoping for things to be as they were may be replaced by a search for new relationships and new activities.

GROWTH

Grief is a chance for personal growth. For many people, it may eventually lead to renewed energy to invest in new activities and new relationships. Some people seek meaning in their loss and get involved in causes or projects that help others.

Some people find a new compassion in themselves as a result of the pain they have suffered. They may become more sensitive to others, thus enabling richer relationships. Others find new strength and independence they never knew they had. After the loss, they find new emotional resources that had not been apparent before.

THE EXPERIENCE OF GRIEF

Grieving people have two choices: they can avoid the pain and all the other emotions associated with their loss and continue on, hoping to forget. This is a risky choice, since experience shows that grief, when ignored, continues to cause pain.

The other choice is to recognize grieving and seek healing and growth. Getting over a loss is slow, hard work. In order for growth to be possible, it is essential to allow oneself to feel all the emotions that arise, as painful as they may be, and to treat oneself with patience and kindness.

FEEL THE PAIN

Give into it – even give it precedence over other emotions and activities, because grief is a pain that will get in the way later if it is ignored. Realize that grief has no timetable; it is cyclical, so expect the emotions to come and go for weeks, months or even years. While a show of strength is admirable, it does not serve the need to express sadness, even when it comes out at unexpected times and places.

TALK ABOUT YOUR SORROW

Take the time to seek comfort from friends who will listen. Let them know you need to talk about your loss. People will understand, although they may not know how to respond. If they change the subject, explain that you need to share your memories and express your sorrow.

FORGIVE YOURSELF

Forgive yourself for all the things you believe you should have said or done. Also forgive yourself for the anger and guilt and embarrassment you may have felt while grieving.

EAT WELL AND EXERCISE

Grief is exhausting. To sustain your energy, be sure to maintain a balanced diet. Exercise is also important in sustaining energy. Find a routine that suits you – perhaps walks or bike rides with friends, or in solitude. Clear your mind and refresh your body.

INDULGE YOURSELF

Take naps, read a good book, listen to your favorite music, get a manicure, go to a ball game, rent a movie. Do something that is frivolous, distracting and that you personally find comforting.

PREPARE FOR HOLIDAYS AND ANNIVERSARIES

Many people feel especially “blue” during these periods, and the anniversary date of the death can be especially painful. Even if you think you’ve progressed, these dates may bring back some of your painful emotions. Make arrangements to be with friends and family members with whom you are comfortable; plan activities that give you an opportunity to mark the anniversary.

GET HELP

Bereavement groups can help you recognize your feelings and put them in perspective. They can also help alleviate the feeling that you are alone. The experiences of sharing with others who are in a similar situation can be comforting and reassuring. Sometimes, new friendships grow through these groups – perhaps even a whole new social network that you did not have before.

There are specialized groups for widowed persons, for parents who have lost a child, for victims of drunken drivers, etc. There are also groups that do not specialize. Check with your local hospice or other bereavement support groups for more information.

If you find that you are in great distress or in long-term depression, individual or group therapy from a counselor who specializes in grief may be advisable. You can ask your doctor for a referral.

TAKE ACTIVE STEPS TO CREATE A NEW LIFE FOR YOURSELF

Give yourself as much time to grieve as you need. Once you find new energy, begin to look for interesting things to do. Take courses, donate time to a cause you support, meet new people, or even find a new job.

It is often tempting to try to replace the person who has been lost. Whether through adoption, remarriage, or other means; this form of reconciliation often does not work.

Many people discover that there is hope after death. Death takes away, but grief can give back. It is possible to recover from grief with new strengths and a new direction. By acting on our grief, we may eventually find peace and purpose.

HELPING THOSE IN GRIEF

You may know someone who has experienced a loss. Many of us feel awkward when someone dies, and don't know what to do or say. The suggestions below are designed to help you help friends, family and coworkers who are grieving.

REACH OUT TO THE GRIEVING PERSON

Show your interest and share your caring feelings. Saying the wrong thing is better than saying nothing at all. At the same time, avoid clichés like “It was God’s will,” or “God never gives us more than we can bear”, or “At least she isn’t suffering.” Do not say you know how it feels. Do say you are sorry and that you are available to listen. Be prepared for emotional feelings yourself. A death generates questions and fears about our own mortality.

LISTEN

Your greatest gift to a grieving person can be your willingness to listen. Ask about the deceased; allowing the person to talk freely without fear of disapproval helps to create healthy memories. It is an important part of healing. While you can't resolve the grief, listening can help.

ASK HOW YOU CAN HELP

Taking over a simple task at home or at work is not only helpful, it also offers reassurance that you care. Be specific in your offer to do something and then follow up with action.

REMEMBER HOLIDAYS AND ANNIVERSARIES

These can be very difficult times for those who are in grief. Do not allow the person to be isolated. Remember to share your home, yourself, or anything that may be of comfort.

SUGGEST ACTIVITIES THAT YOU CAN DO TOGETHER

Walking, biking or other exercises can be an opportunity to talk, and a good source of energy for a tired body and mind.

HELP THE GRIEVING PERSON FIND NEW ACTIVITIES AND FRIENDS

Include grieving people in your life. Grieving people may require some encouragement to get back into social situations. Be persistent, but try not to press them to participate before they are ready.

PAY ATTENTION TO DANGER SIGNS

Signs that the grieving person is in distress might include weight loss, substance abuse, depression, prolonged sleep disorders, physical problems, talk about suicide, and lack of personal hygiene.

Observing these signs may mean the grieving person needs professional help. If you feel this is the case, a suggestion from you (if you feel close enough to the person), or from a trusted friend or family member may be appropriate. You might also want to point out community resources that may be helpful.

Death can be a painful and permanent loss experience, and one of the hardest from which to recover. Death takes away, but facing it and grieving can result in peace, new strengths and purpose.

KNOWLEDGE OF GRIEF

“There can be no knowledge without emotion. We may be aware of a truth, yet until we have felt its force, it is not ours. To the cognition of the brain must be added the experience of the soul.”
No amount of knowledge can prepare us for bereavement.

Grief is the most intense and enduring emotion we can experience. No quick fix. No short-cut. An ancient African saying is “There is no way out of the desert except through it.” Knowledge of the grief process gives us a much generalized map of the terrain we have to cover. Each of us will take a different route. Each will choose his own landmarks. He will travel at his own unique speed and will navigate using the tools provided by his culture, experience, and faith. In the end, he will be forever changed by his journey.

Knowledge helps us avoid the major pitfalls of grief. Knowledge of what is known of grief assures us that we have not lost all sense of sanity. When we find ourselves feeling befuddled in a mist shrouded swamp we can say “It’s OK. This too is part of my journey. Others have gone this way before me and I will survive. I am human.”

THE MECHANICS OF GRIEF

Several blueprints or theories about grief have been proposed. Sigmund Freud began with the concept of having to do ‘grief work’. That is, a specific job should be finished before the next job begins. Stages of grief theories abound. Depending on the writer, 4 to 12 stages of grief are described. The 4 tasks of mourning are also described: Accepting the reality of the loss, experiencing the pain, adjusting to a life without your loved one and finally being able to invest your emotional energy into a new life.

Grief or bereavement theories are the generalized maps discussed earlier. Each theory is an attempt by a caring investigator to understand and guide us through our pain. However, humans are unique and cannot be forced into particular patterns of behavior. You will travel through grief at your own speed using your appropriate route.

Let a circle represent a stage, phase, or piece of work. It can be denial, shock, anger, resolution, confusion, numbness, a behavior or whatever you are feeling right now. Add a second circle and let it overlap the first. Give it another name; perhaps what you were feeling yesterday, last week or one hour ago. Continue adding circles that overlap and represent emotions, physical sensations, cognition or behaviors that belong to you.

This is grief’s blueprint. You may feel secure and at peace one moment and find yourself in the paralyzing center of all the overlapping elements of grief the next. It’s OK. It’s human.

WHAT ARE THESE ELEMENTS OF GRIEF?

There is no complete list of the experiences that comprise grief. The common ones are emotional, physical sensations, behaviors and cognitions. Cognition refers to the way you think and how information is processed by your brain. How you experience grief will be unique to you and will be affected by several factors. Some are discussed below:

Who died?

The death of a member of your softball team will have a different impact on you than the death of a spouse.

What was your relationship with the deceased?

To say “My wife has died.” just begins to describe your relationship and the extent of your grief. Have you lost your best friend? Accountant? Confidant? Interior Decorator? The mother of your child? Sexual partner? Did her death leave unresolved conflict?

What was the cause of death?

The expected death of an aging grandparent on a life support system and in great pain creates a grief reaction different than the unexpected, traumatic death of a child or the suicide of a family member.

These are a few of the variables that make each grief experience different. Use a shotgun as a disconcerting but graphic analogy. It can fire a mixed load of pellets at high velocity. As the pellets travel through the air they slow down and spread out. A target very close to the muzzle of the gun will be deeply penetrated by most of the pellets in a compact, destructive pattern

A distant target may have a few pellets barely penetrate or bounce off its surface. Some men, when trying to describe the impact death has on them have used the phrase “I feel like a shotgun has blown a hole right through me.” This is a fitting analogy. Researchers have compared the psychological effect of bereavement to physical wounding.

How the human body heals itself depends on the nature of the wound, the extent of the damage, the medical assistance available and the health of the victim. They may recover fully or experience some physical disability or permanent limitation. So it is with grief. Mourning is grief’s time of healing.

MOURNING

Emotions

- **Sadness:** This is the most common emotion and one we are all familiar with to some degree.

- **Anger:** You may be angry at God, the doctor, the 'system', even the person who died. Someone you love is gone. Why should you not feel angry?
- **Frustration:** Death is final. You want your loved one back and you can do nothing.
- **Guilt:** The questions may come up. "Maybe I should have?" "If only I had...?"
- **Shock and Numbness:** Initially you may feel nothing. Combat veterans are often surprised to discover their wounds following an action. Accident victims may become aware of their own injuries after they have cared for others.

Physical Sensations

- General sense of fatigue or weakness:
- Shortness of breath or tightness in your chest
- Dry mouth

Men often describe their emotional feelings in physical terms. "It knocked the wind out of me.", "Hit me right between the eyes", or "Her death just crushed me." are common examples.

Behaviors

- Loss of appetite
- Insomnia
- Retreating socially
- Crying
- Dreams or nightmares
- Calling out the deceased's name
- Treasuring or avoiding mementos of the deceased

Cognition seems to cause men the most difficulty. Some experiences may lead you to think you are 'going crazy'. You are not! Your mind and heart are simply not ready to 'let go' of the dead. In time, these sometimes confusing or frightening experiences will pass.

- **Hallucinations:** You may hear her voice, the sound of his footstep; see glimpses of your child moving in a room. These can be triggered by normal sounds, a scent that reminds you of the aroma of her perfume, or the simple objects used in everyday life.
- **Spiritual Emptiness:** Your religious faith may be a source of comfort or disillusionment. Speak to your religious leader or find a spiritual advisor if you feel the need.
- **Absent mindedness or preoccupation is common.** The 3 days normally granted by employers mark the beginning of your mourning. It will take considerably longer for you to resolve your grief. **Caution:** Work involving power tools, heavy equipment or driving can be extremely dangerous following the death of a loved one. If you find yourself preoccupied with thoughts of the one you loved and lost, stop your car or truck, shut

down any heavy machinery and move to a safe area. Let yourself cry in the privacy of your vehicle. Do a 'walk around check'. Give all 18 tires a good kick! Don't drive while under the influence of your emotions.

- **Depression and Grief:** Many grief experiences are similar to those of a major depression. Depression is a natural reaction to the death of a loved one. This type of depression is called a reactive depression. It occurs as a reaction to a specific event and its duration and intensity varies. In the blueprint of your grief are moments of wonderful, joyous laughter as you recall great times and humorous incidents. An immediate sense of depression may follow the laughter. This is normal. Your emotional roller coaster ride will gradually and gently slow down and level off. Occasionally, a grief event may lead to a full clinical depression requiring medical intervention.
- **Alcohol and Drugs:** Alcohol is a depressant drug. The term "Crying in his beer." is a valid observation. The use of drugs and alcohol to "numb the pain" simply make the pain last longer and can lead to severe complications. A toast to the departed or sharing a drink while talking to an understanding friend probably poses no danger. Using alcohol or drugs to sleep, or "get me through the day" is cause for major concern. Be gentle with yourself.

You may experience some of these human phenomena for a surprisingly long time. With each passing day, as you explore and understand your loss, they will diminish in frequency and intensity. The most important tool you have for recovery is to talk with accepting, understanding friends about your loss.

WHAT WE NEED DURING GRIEF

Time alone; and time with others whom we trust and who will listen when we need to talk. We need lots of time; months and years of time; to feel and to understand the feelings that go along with our loss.

Rest, Relaxation, Exercise, Nourishment, Diversion: You may need extra amounts of things you needed before. Hot baths, afternoon naps, a trip, a "cause" to work for to help others – any of these may give you a lift. Grief is an exhausting process emotionally. You need to replenish yourself. Follow what feels healing to you and what connects you to the people and things you love.

Security: Try to reduce stress or find help for financial and other stresses in your life. Allow yourself to be close to those you trust. Getting back into a routine is helpful. You may need to replenish yourself to do things at your own pace.

Hope: You may find hope and comfort from those who have experienced a similar loss. Knowing some things that helped them, and realizing that they have recovered and time does help, may give you hope that sometime in the future your grief will be less raw and painful.

Caring: Try to allow yourself to accept the expressions of caring from others. They may give you hope that sometime in the future your grief will be less raw and painful.

Goals: For a while, it will seem that much of life is without meaning. At times like these, small goals are helpful. Something to look forward to, like playing tennis with a friend next week, a movie tomorrow night, a trip next month, helps you get through the time in the immediate future. Living one day at a time is the rule of thumb.

At first, don't be surprised if your enjoyment of these things is not the same. This is normal. As time passes you may need to work on some longer range goals to give some structure and direction to your life. You may need guidance or counseling to help with this.

Small Pleasures: Do not underestimate the healing effects of small pleasures when you are ready. Sunsets, a walk in the woods, a favorite food – all are small steps towards regaining your pleasure in life itself.

Affirmations: Positive statements that are repeated or written to oneself until they have “taken root” or been established in the mind. At first, you may not believe that you have large amounts of the qualities listed below. Nevertheless, begin by assuming that you do have some of all of these qualities – enough to have brought you this far. Picture what life will be like if you possess them to an even greater degree.

Courage: Acknowledge the courage which has enabled you to face your feelings. Courage is being afraid, but doing it anyway. Keep the courage!

Patience: Accept that you will not always be strong and that grief will take time.

Resilience: The capacity to bounce back from stress and go on is something that can be learned; ability increases with experience and age.

Perseverance and Endurance: Have the faith that lasting through the pain will get you through.

Capacity to distance: It can be helpful to step back and view life from afar; see what has happened, is happening and can happen. Move ahead!

Sense of humor: Regaining your ability to smile and laugh is not a betrayal of your pain; grief is a curious mixture of many emotions. Laughter and humor may provide some necessary relief and strength for the suffering you are experiencing.

Openness to others: Many people say that without friends and relatives to support them, they would have had far more pain and loneliness during their period of grief. Choose your confidants carefully and use them. You may be wise to choose more than one.

Writing down affirmations seems to have certain advantages. When we write affirmations, the mind, hand, and eye are all involved. Many people resist the notion of writing because it sounds

so simple, but it is perhaps because of simplicity that this method often works so powerfully for many people.

These are some possible affirmations you may choose to guide your approach to life from now on. Try creating some of your own:

- I cherish each moment of my life.
- I am not hiding my love from people.
- I resolve to help my friends in need of support.
- I am strong. I can grow from pain.
- I intend to live my life to the fullest: my time is precious.
- I will become open to new pathways and new relationships.
- I am learning.

NOTES

NOTES

Module 8
Hospice Manual
Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. List seven factors that may increase the risk of developing complicated grief.

2. List and explain the elements to the determinant of grief.

3. Not being able to make decisions is which type of reaction to grief?
A. Shock
B. Disbelief
C. Anger
D. Guilt

4. Some estimates suggest that as few as _____ or as many as _____ of bereaved people develop complicated grief. (Fill in the blanks.)

5. Grievers with _____ personalities cry and want to be in touch with the emotions of grief. Those with more cognitive personalities tend to process grief in a more logical, orderly manner. _____ may not want to dwell on something that cannot be changed, such as the death of a loved one. (Fill in the blanks.)

MODULE 9: COMPASSION FATIGUE

Compassion fatigue is a term generally applied to care givers that work in intense fields. Those who work in the fields of death, trauma, mental illness, surgery, emergency medicine, obstetrics, and rural general practitioners are particularly at risk. Others at risk for compassion fatigue are exposed to second-hand stress – journalists, clergy, law enforcement officers, military personnel and emergency medical responders.

Compassion fatigue is defined as: A state experienced by those helping people in distress; it is an extreme state of tension and preoccupation with the suffering of those being helped, to the degree that it is traumatizing for the helper. A deep physical, emotional and spiritual exhaustion accompanied by acute emotional pain. A reaction experienced by care givers who suffer trauma from the event(s) that have traumatized their patients.

Compassion fatigue is **not** “burnout”, which results from increased workload and institutional stress; nor is it “counter-transference”, though counter-transference may co-occur with compassion fatigue.

Compassion fatigue is also sometimes called Vicarious Traumatization or Secondary Trauma because the caregiver suffers because of the trauma experienced by the patient.

WHO IS AT-RISK FOR COMPASSION FATIGUE?

Compassion fatigue may occur in a wide range of persons involved in providing aid to others. It has been found to be most prevalent among professionals and personal family members, friends, and associates of trauma survivors.

Psychologists, social workers, hospice chaplains, lawyers, disaster relief workers, nurses, psychiatrists, medical doctors, emergency service professionals, police, crisis phone-line attendants and shelter workers among others, are all susceptible to Compassion Fatigue.

When the counselor has encountered trauma through first-hand exposure this further heightens vulnerability to Compassion Fatigue. Just as it is not uncommon to find ex-substance abusers counseling those currently trying to break away from addictions; likewise, it is not uncommon to find those who are personally knowledgeable about trauma trying to aid others who have faced terrible events.

We urge these caregivers to develop and maintain good self-care disciplines and also complete a periodic self-assessment of compassion fatigue symptoms using the Compassion Fatigue Scale-Revised.

WHY ME?

Those who have a history of trauma are more vulnerable to compassion fatigue. Those caregivers who are inexperienced, who fear not being able to do their jobs, or those who are afraid of what they might see are more vulnerable. Caregivers who are in danger themselves – field medics, first responders – suffer heightened probability for compassion fatigue.

Chaplains, counselors, therapists; we all suffer to some degree. We have not been directly exposed to the trauma scene, but we hear the story told with such intensity, or we hear similar stories so often, or we have the gift and curse of extreme empathy and we suffer. We feel the feelings of our patients. We experience their fears. We dream their dreams. Eventually, we lose a certain spark of optimism, humor and hope. We tire. We aren't sick, but we aren't ourselves.

COMPASSION IN CRISES

Demonstrating compassion is being present in the suffering. “Compassion is the cardinal virtue of the clergy tradition, the indispensable quality that motivates and deepens all charitable, healing, and caring acts into events of moral and spiritual significance.

The compassionate chaplain is, therefore, one who exemplifies a deeply felt sense of solidarity with suffering persons transcending class and culture, yet one who maintains the distance necessary for sustaining suffering persons in their search for an authentic understanding of the meaning of their afflictions.”

The chaplain in disasters must know his or her own biases, needs, and limitations and still deeply desire to identify with the disenfranchised and the wounded; seeking to demonstrate compassion as the priority of disaster ministry.

Merely attempting to prevent suffering or not be the cause of suffering will be inadequate. The chaplain in disasters must approach ministry from a radically different paradigm – the chaplain must initiate and be an active participant in “being” compassion as a priority and “doing” compassion as a necessity.

Recognizing his own natural instinct to excuse himself from the crisis, the chaplain must still choose to become engaged in the suffering. The significance of being compassionate may lay in the fact that being compassionate is not an activity one naturally seeks, but an activity that one must intentionally choose, knowing that it “feels” contrary to natural instincts.

There is a natural resistance humans have toward pain – one avoids it whenever possible. The emotionally healthy individual does not intentionally cause oneself unnecessary pain. One naturally seeks safety, shelter, and nourishment as self-preservation before seeking to meet the needs of others.

Therefore, one must be aware that choosing to serve as a chaplain will not be for everyone. Only a few will choose to enter this place of suffering with victims of disasters – often these victims

will be strangers, and sometimes they will be the perpetrators of the disaster itself (e.g., the Colorado wildfire arsonist became trapped and became a psychologically traumatized victim).

For the chaplain in disasters, the response of “being present in suffering” is an intentional choice to be uncomfortable, and the choice grows out of the center of the chaplain’s personal feelings and emotions – from his “guts.”

Demonstrating compassion is an act of intention and an intention to act. It is intentionally entering a place of crisis and full immersion in the human condition. Demonstrating compassion may be risky.

THERE IS A COST TO CARING

Professionals who listen to the stories of fear, pain and suffering of others may feel similar fear, pain and suffering because they care. Professionals especially vulnerable to compassion fatigue include emergency care workers, counselors, mental health professionals, medical professionals, clergy, advocate volunteers, and human service workers. If you ever feel as though you are losing your sense of self to the clients you serve- you may be suffering from compassion fatigue.

The concept of compassion fatigue emerged only in the last several years in the professional literature. It represents the cost of caring about and for traumatized people. Compassion fatigue is the emotional residue of exposure to working with the suffering; particularly those suffering from the consequences of traumatic events. Professionals who work with people, particularly people who are suffering, must contend with not only the normal stress or dissatisfaction of work, but also with the emotional and personal feelings for the suffering.

Compassion fatigue is **not** burnout. Burnout is associated with stress and hassles involved in your work; it is very cumulative, is relatively predictable and frequently a vacation or change of job helps a great deal. Compassion fatigue is very different.

Compassion fatigue is a state of tension and preoccupation with the individual or cumulative trauma of patients as manifested in one or more ways including re-experiencing the traumatic event, avoidance/numbing of reminders of the event, and persistent arousal. Although similar to critical incident stress (being traumatized by something you actually experience or see), with compassion fatigue you are absorbing the trauma through the eyes and ears of others. It can be also thought of as secondary post-traumatic stress.

There are human costs associated with compassion fatigue. Job performance goes down, mistakes go up. Morale drops and personal relationships are affected – people’s home lives start to deteriorate, personality deteriorates and eventually it can lead to overall decline in general health.

The notion that working with people in pain extracts a significant cost from the caregiver is not new. Although the costs vary and have been lamented from time immemorial, anyone who has sat at the bedside of a seriously ill, or recently bereaved, loved one knows the toll involved in devoting singular attention to the needs of another suffering person.

Only in recent years, however, has there been a substantial effort to examine the effects on the caregiver; of bearing witness to the indescribable wounds inflicted by traumatic experiences. The exploration and examination of these effects evolved throughout the last century and comes to us from a wide variety of sources.

One of the first earliest references in the scientific literature regarding this cost of caring comes from Carl G. Jung in *The Psychology of Dementia Praecox* (Jung, 1907). In this text, Jung discusses the challenges of counter transference – the therapist’s conscious and unconscious reactions to the patient in the therapeutic situation – and the particular counter transferential difficulties analysts encounter when working with psychotic patients.

He boldly prescribes a treatment stance in which the therapist participates in the delusional fantasies and hallucinations with the patient. Nevertheless, he warns that this participation in the patient’s darkly painful fantasy world of traumatic images has significant deleterious effects for the therapist; especially the neophyte and/or the therapist who has not resolved his/her own developmental and traumatic issues.

Recent texts have suggested that therapists sometimes experience counter transference reactions that imitate the symptoms of their clients. For instance, when working with survivors of traumatic experiences, authors have reported counter transference phenomena that mimic the symptoms of posttraumatic stress disorder (PTSD; Lindy, 1988; Wilson & Lindy, 1994; Pearlman & Saakvitne, 1995).

Business and industry, with their progressive focus upon productivity in the last half of the twentieth century, have provided us with the concept of burnout (Fruedenberger, 1974; Maslach, 1976) to describe the deleterious effects the environmental demands of the workplace have on the worker.

Burnout, or “the syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment” (Maslach, 1976, p. 56), has been used to describe the chronic effects that psychotherapists suffer as a result of interactions with their clients and/or the demands of their workplace.

Research has shown that therapists are particularly vulnerable to burnout because of personal isolation, ambiguous successes and the emotional drain of remaining empathetic. Moreover, burnout not only is psychologically debilitating to therapists, but also impairs the capacity to deliver competent services. The literature on burnout, with its twenty-five year history, thoroughly describes the phenomena and prescribes preventive and treatment interventions for helping professionals.

The study of the effects of trauma has also promoted a better understanding of the negative effects of helping. Psychological reactions to trauma have been described over the past one hundred and fifty years by various names such as “shell shock”, “combat neurosis”, “railroad spine”, and “combat fatigue” (Shalev, Bonne, & Eth, 1996). However, not until 1980 was the latest designation for these reactions, posttraumatic stress disorder (PTSD), formally recognized as an anxiety disorder in the Diagnostic and Statistical Manual of Mental Disorders-III (DSM-III, American Psychiatric Association, 1980; Matsakis, 1994).

Since that time, research into posttraumatic stress has grown at an exponential rate and the field of traumatology has been established with two of its own journals, several professional organizations, and a unique professional identity.

As workers are increasingly called upon to assist survivors of violent crime, natural disasters, childhood abuse, torture, acts of genocide, political persecution, war, and now terrorism, discussion regarding the reactions of workers and other helpers to working with trauma survivors has recently emerged in the traumatology literature.

Professionals who listen to reports of trauma, horror, human cruelty and extreme loss can become overwhelmed and may begin to experience feelings of fear, pain and suffering similar to that of their clients. They may also experience PTSD symptoms similar to their clients', such as intrusive thoughts, nightmares, avoidance and arousal, as well as changes in their relationships to their selves, their families, friends and communities. Therefore, they may themselves come to need assistance to cope with the effects of listening to others' traumatic experiences.

While the empirical literature has been slow to develop in this area, there is an emerging body of scientific publications that attempts to identify and define the traumatization of helpers through their efforts of helping. The terms “vicarious traumatization”, “secondary traumatic stress” and “compassion fatigue” have all become cornerstones in the vernacular of describing the deleterious effects that helpers suffer when working with trauma survivors.

Vicarious traumatization refers to the transmission of traumatic stress through observation and/or hearing others' stories of traumatic events and the resultant shift/distortions that occur in the caregiver's perceptual and meaning systems. Secondary traumatic stress occurs when one is exposed to extreme events directly experienced by another and becomes overwhelmed by this secondary exposure to trauma.

Several theories have been offered but none has been able to conclusively demonstrate the mechanism that accounts for the transmission of traumatic stress from one individual to another. It has been hypothesized that the caregiver's level of empathy with the traumatized individual plays a significant role in this transmission and there is some budding empirical data to support this hypothesis.

The combined effects of the caregiver's continuous visualizing of clients' traumatic images added to the effects of burnout can create a condition progressively debilitating the caregiver. This construct holds that exposure to clients' stories of traumatization can produce a form of posttraumatic stress disorder in which Criterion A, or “the event” criterion, is met through

listening to, instead of the in vivo experiencing of, a traumatic event. The symptoms of compassion fatigue are divided into categories of intrusive, avoidance, and arousal symptoms.

Many caregivers, especially those providing on-site services, will have had first-hand exposure to the traumatic event(s) to which they are responding. For many, these symptoms of PTSD will have a delayed onset and not become manifest until sometime later.

It has also been found that many caregivers enter the service field with a host of traumatic experiences in their developmental past. There may have been no symptoms associated with these events, or the symptoms related to them may have remained sub-clinical. However, it has been observed that as these caregivers begin to encounter the traumatic material presented by clients, many of them begin to develop clinical PTSD symptoms associated with their previously “benign” historical experiences.

In the efforts to treat compassion fatigue, it was concluded that it is often necessary to successfully address and resolve primary traumatic stress before addressing any issues of secondary traumatic stress and/or burnout. Additionally, an interactive, or synergistic, effect among primary traumatic stress, secondary traumatic stress, and burnout symptoms in the life of an afflicted caregiver has been discerned.

Experiencing symptoms from any one of these three sources appears to diminish resiliency and lower thresholds for the adverse impact of the other two. This seems to lead to a rapid onset of severe symptoms that can become extremely debilitating to the caregiver within a very short period of time.

THE PATH TO WELLNESS

Once you realize that you are a candidate for compassion fatigue, or are already suffering its effects, exploring this new awareness can lead to insights concerning past traumas, pain, and defeating behaviors.

A common and understandable coping mechanism in care giving is to simply *stuff* the overwhelming emotions that surface repeatedly in your work. How else can you keep going? Eventually, those emotions refuse to be ignored. All too often, psychological and physical crises occur.

With support, insightful information, and authentic self-care, you can begin to understand the complexity of the emotions you've been juggling and, most likely, suppressing. Most people never take the time to understand how their jobs affect them emotionally. Give yourself credit for moving forward and affecting change. Your hard work will pay off.

Authentic self care begins with the following:

- Be kind to yourself.

- Enhance your awareness with education.
- Accept where you are on your path at all times.
- Understand that those close to you may not be there when you need them most.
- Exchange information and feelings with people who can validate you.
- Listen to others who are suffering.
- Clarify your personal boundaries. What works for you; what doesn't?
- Express your needs verbally.
- Take positive action to change your environment.

They line up, miles and miles of misery. Days blur into nights and still, they keep coming. No end in sight. Whether “they” are hurricane evacuees, earthquake survivors, Tsunami victims, African orphans, or wounded soldiers, they stretch for miles.

And at the front of this line is a weary but dedicated physician, housewife, government worker, firefighter, M.A.S.H. nurse, or hospice worker who has not slept, called home, showered, eaten more than one cold French fry at a time in, what day is it? Which disaster is this, again?

Finally, the shift ends and that worker goes straight to the office, home, pays bills, helps with homework, schedules regular routine, counsels her normal clientele and little by little, our Good Samaritans leave pieces of themselves scattered like ash. Without even realizing it, our compassion burns out.

“But who is behind the rescuer? It is a very lonely place to be.” It’s called compassion fatigue.

Humans are remarkable in our urge, passion, and our imperative to help. Without compensation or reward, our inner Samaritan propels us into the fray, the fire, the flood, without thought or regard to our own sacrifices. And, we make a difference! We are energized, adrenalized, humbled, and forever bonded to our new brother who was, just yesterday, a stranger.

Then the threads of guilt begin to tangle and pull us down. “When I finally went home to my warm, safe house, to my family and friends,” says Katrina relief volunteers Barbara Elk, “the guilt was overwhelming. I wasn’t doing enough, giving enough. It’s just very hard to give yourself permission to let go, even for a little while.”

Eventually numbness may ooze over us. We sleepwalk through our days, become inured, even cynical. One “hurricane” replaces another, and before we know it, we arrive at the conclusion that we are too tiny to make a difference. And frankly, we’re too tired to care.

COMPASSION FATIGUE SYMPTOMS

Whether you are a paid professional, a volunteer or both, the symptoms are similar. Any of these symptoms could be signaling the presence of compassion fatigue.

- Blaming “them” (whoever they are)
- Chronic tardiness
- Decreased functioning in non-professional situations
- Depression, hopelessness
- Difficulty separating work life from personal life
- Diminished balance between empathy and objectivity
- Diminished ego-functioning (time, identity, volition)
- Diminished joy toward persons/activities that used to bring you happiness
- Diminished sense of personal accomplishment
- Diminished sense of purpose/enjoyment with career,
- Dread of working with certain people
- Exhaustion (physical and emotional)
- Feelings of therapeutic impotence or de-skilled with certain clients
- Free-floating anger or misplaced anger
- Frequent headaches
- Frequent vague illnesses
- Gastrointestinal complaints
- Hypertension
- Hyper vigilance
- Increase in ineffective and/or self-destructive self-soothing behaviors
- Increased irritability
- Increased negative arousal
- Insomnia, sleep disturbances
- Intrusive thoughts/images of situations/traumas
- Loss of hope
- Low self-esteem
- Lowered frustration tolerance/outbursts of anger or rage
- Marked or increasing transference / counter transference issues with certain people
- Obsessive worry that you aren’t doing enough; irrationally high self-expectation
- Substance abuse, including food, alcohol, drugs
- Workaholism

Health care providers in intense fields – trauma, mental illness, obstetrics, and rural general practitioners – are particularly at risk. So are journalists, clergy, law enforcement officers, military personnel and emergency responders; and so are janitors, secretaries, accountants or garbage truck drivers who work triple shifts in crises or simply must answer the call to help.

The eruption of violence, personal degradation, and physical/ psychological violations disrupt our notions of the sanctity of our assumptive world. Such traumas can result in symptoms of

Post-traumatic Stress Disorder. Post-traumatic stress effects individuals differently but is identified by three categories of symptoms:

- (1) Intrusive thoughts, images and sensations
- (2) Avoidance of people, places, things and experiences which elicit memories of the traumatic experience
- (3) Negative arousal in the forms hyper-vigilance, sleep disturbances, irritability and anxiety.

These symptoms combine to form a state of physical, emotional, cognitive and spiritual volatility in traumatized individuals, families and groups. Persons who work closely with these groups and individuals are vulnerable to the contagion of this volatility.

Some caregivers appear to be more resilient than others to the transmission of traumatic stress; however, any caregiver who continually works with traumatized individuals is at-risk for compassion fatigue.

“I’VE GOT TO DO SOMETHING”

We humans dislike feeling helpless. “As long as we can do something, we feel better,” says psychologist Dr. Camille Lloyd, director of student counseling at The University of Texas Health Science Center at Houston. “It gives us a sense of control over our environment – and ultimately our own destinies,” even if it is only limited control.

“That first surge of emotion that tells us we can indeed perform rescue in our own small ways is empowering,” But you can’t keep that momentum going. It is draining and there is an emotional law of diminishing return.”

The “feel-good” begins to wear off for several reasons. “People in need are often fractious, frantic, and not appreciative because they have simply lost so much. The untrained volunteer may react emotionally to what appears to be ingratitude.

COMPASSION OVERDOSE

Sometimes we just aren’t prepared for the emotional onslaught. “Med students, for instance, are learning to cope with horrific illness and trauma at the very same time they are learning how to feel adequately skilled enough to help.

“Sometimes it’s their first contact with genuine human suffering. Students tend either to immerse themselves in another’s struggle, to the point where it takes a personal toll, or become overly detached as a way of defending themselves against the painful situation. They soon have to learn to find a way to empathize and care without becoming demoralized or overwhelmed themselves.

Maybe it’s a little like learning to throw someone in trouble a life preserver rather than impulsively jumping in and risking both people drowning.

GUILT

It's simple: we're safe, they're not. We have our homes, our legs, our children. They don't. It could be us next time. We have to do more and more and it's still not enough. The only way to make it good enough is to have made it 'not happen,' which is as irrational as thinking we can fix it all ourselves.

Health professionals, emergency responders and chaplains are the most vulnerable to compassion-associated guilt. If we have chosen those fields, we are by nature a bit omnipotent in our thinking.

“There are huge expectations placed upon health providers by society to show compassion, but remain impervious to suffering, to remain detached, yet caring. We are taught to be at the top of the pyramid to be the ones who lead the rescue. But who is behind the rescuer? It is a very lonely place to be.”

Lay volunteers sometimes just don't know when to stop. Reality is the best guilt antidote. Even when you were 'doing it all, 24/7' you could not possibly solve the whole problem,” “So you do what you can.”

CRASH AND BURN

During the 1989 Phillips Petroleum plant explosions in Pasadena, Texas, numerous medical, psychiatric and emergency personnel worked around the clock for 90 days to provide counseling and supportive measures to more than 100 employees and their families.

Six months to a year later, after lives were on track, depression set in for many workers. Survivors returned for help, just when life was “supposed to be normal” and physicians and counselors reported a low-grade fatigue. Post-traumatic stress affects the healer as well as the healed.

“A patient will come in to the ER, triggering the physician's or nurse's memories of a personal trauma or bad experience, and suddenly the health provider experiences a cascade of disturbing memories and emotions. We need to remember that as human beings, we, too, are susceptible to trauma and stress,”

THE NEW NORMAL

Does anyone remember the names of the twelve hurricanes last year? Probably not. The last mudslide in California? Where the most recent earthquake hit? Whether disaster is manmade, such as terrorism or natural, like back-to-back hurricanes, we must adjust to a new normal.

“Which means that systems must be in place for first responders to minimize confusion, stress and anxiety for victim and volunteer, alike.”

“Through the Katrina and Rita experiences, plans are evolving. Medical and nursing schools must do a better job of preparing their professionals for disaster relief and have mandatory stress management programs in place all the time, not just during crisis.”

It's been just a few months since Hurricane Katrina tested the mettle of thousands of volunteers. One month later, Rita happened; then Stan, then Wilma and those were just the hurricanes; and only a few of them. Volunteer shifts doubled. More shelters opened. Field medical clinics migrated to yet another Ground Zero. Relief workers are still waiting to exhale.

Compassion Fatigue is experienced by volunteers, chaplains, health care professionals, and emergency workers those who give themselves fully to the needy and helpless – to the detriment of themselves. Most often, compassion fatigue occurs when catastrophe drags volunteers into utter exhaustion or when the sheer magnitude of human suffering emotionally drowns the volunteer.

The new reality seems to be, not if, but when the next crisis strikes. So, we had better catch our second wind. Here's how.

DON'T FALL INTO THE GUILT TRAP

Guilt is useful, in appropriate doses. It serves as a reminder, an alarm bell that goes off to alert you of something you ought to be doing. When your guilt is disproportionate to your role, it becomes paralyzing and intrusive, in the case of volunteer work.

Say to yourself:

- I can do a small piece, but I can't do all of it.
- Even when I was working back-to-back shifts, I wasn't solving the problem.
- I can't accomplish it all, so I might as well do what I can do.
- As much as I'd like to believe that I am capable of saving everyone, I'm just not that powerful.
- Buying diapers for a shelter seems so small a contribution. But not to the young mother who desperately needs diapers.
- I am not so essential that the world cannot turn without me tonight. I can be replaced if I need a break.

The best way to honor those that have been caring for is to appreciate what you have, home, family, job, and health. To have guilt because you are not ill, displaced or homeless dishonors those who have lost so much.

Remember the age-old advice: “You are of no good to anyone if you can't take care of yourself, first.” If that doesn't hit home, try this one: “Why would someone want you to take care of them when you don't like yourself enough to do the same?” And finally: “If you must put yourself on a guilt trip, look at the guilt, you were never home.” (Now there's useful guilt.)

If you find yourself feeling guilty because you want your own routine to return to normal, let yourself off the hook. That's human and expected. If you find yourself losing empathy, growing cynical toward the very people you're trying to help, it is time for a break. Take it.

FIND BALANCE

Balance: We hear it preached so often, it becomes cliché; background noise. Yet, like homeostasis, the ultimate microcosm, we must find it in our lives or we will die. It is that simple. If even thinking about striking a healthy balance between serving others and preserving yourself gives you a panic attacks, fill this prescription.

Write down what you have done that day in a log: for instance, how many survivors you saw in your normal day; how many hours you spent working a shelter; how long you spent with your children; your spouse; how many meals you ate; bills you paid; hours you slept.

Anyone who has raised children knows about the "time-out" chair. The Worry "chair" is the opposite of that. People who have a tendency to obsess about a thought as if it's on a continuous feedback loop must learn to compartmentalize their worries so that they don't interfere with life.

Find a place in your home or office that you rarely occupy. It can be the other side of your desk or an occasional chair; or set aside a particular time of day, say 3:00 P.M. to 3:20 P.M. Keep this appointment with yourself, make it as important as a patient, a test, a child's reading time.

Now, let it pour out of you, all the worry, guilt, what-ifs, and if-only. Hold nothing back. Imagine every possible scenario that intrudes on you day and night and funnel it into that 20-minute period.

When the bell goes off, when you leave that "chair" – real or metaphoric, you are done, finished until your next appointment with yourself. When you're tempted to let those thoughts crawl across your mind, remind yourself that you have 20 minutes to address them – tomorrow.

RESCUING THE RESCUERS

Recognition that our health care workers are just as vulnerable to critical stress as the rest of us might head off burnout. Even in the absence of catastrophic events, physicians, nurses, paramedics, and hospice chaplains are seeking early retirement more often and at younger ages.

Managed health care, mountainous paperwork, a litigious environment, the pressure to see twice as many patients in half the time are robbing health professionals of their original "calling." Add a national disaster to the mix, and the best of our Samaritans may need rescue.

Yet, also on the rise are programs such as stress management, cognitive therapy, "renewal" seminars, and relaxation techniques that are making their way into mainstream medicine – not just for patients, but for the healers.

Dr. Robert Guynn, chairman of the University of Texas-Houston medical school's Department of Psychiatry and Behavioral Sciences, urges health professionals and those in high-stress relief work to find a stress management system that works for them. "Different techniques work for different personality types. 'Knowing thyself' is the first step."

COGNITIVE TECHNIQUES

KNOW THYSELF

This approach centers on self awareness, becoming cognizant of how you respond to stress. The self-conversation would go like this:

"Knowing how you react to stress, without judging it, allows you to change your response. You can consciously restructure your approach. At calmer times, we can pay attention to the triggers that set us off and have techniques in place to ward off destructive or counterproductive behaviors."

TALK

What we see in the field can be horrific. It's often tough to shake those images and sometimes the best thing we can do for ourselves is to talk about it with someone who has been where we've been, seen what we've seen.

Professional "renewal" groups are springing up around the country in many academic settings. A lot of departments now foster just such a program, where professionals can share and shed their burdens in a non-judgmental and supportive atmosphere. The object is not to solve each other's problems, but simply to listen and be present with another colleague's experiences.

At the end of an hour of quiet reflection with those whom you've grown to trust, there's a sense of regained balance, of 'renewal.' If we don't find the right balance between self-care and care for others, we can slip into fantasies of heroism or martyrdom which can be harmful to ourselves, our colleagues and families, and those we care for.

PREPAREDNESS: ANTIDOTE TO STRESS

Working non-stop double shifts during a disaster like Katrina and Rita would deplete any volunteer to the point of meltdown, but, what would make it worse was "you're also doing it without a plan already on the shelf that we could pull off, open up and put in place."

In the initial stages, each shift starts from scratch, from creating records to simply lining up instruments and supplies. There is no consistency, which is essential in triage and follow-up.

Volunteers work out the kinks; volunteer and chaplain personnel adapt to the chaos, climbing huge learning curves. Next time you will have an equation: five emergency physicians, four nurses per 'x' number of patients per shift. You will still be tired, but you can put our energies to proper use.

Coming up with "The Plan" is a bit like writing a science fiction script. You may feel foolish and certainly helpless while pitching scenarios. Yet, you now know that you must have a plan for the absolute worst case – a total loss of the local governmental infrastructure.

"Every major city should have a plan to activate a temporary alternate seat of government. This alternate command post should be located a safe distance – probably several hundred miles – away from the city. If these officials could not reestablish contact with the local chief executive after a disaster, they could take charge and begin to initiate requests for relief and emergency resources."

If every major city had a plan for facing such a worst-case scenario, 99.9 percent of the strategies would never be used, but the one time in a thousand when it is needed, the plan could save hundreds of lives and prevent unnecessary suffering.

RECOVERY PROGRAM FOR COMPASSION FATIGUE

"The professional work centered on the relief of the emotional suffering of clients automatically includes absorbing information that is about suffering; often it includes absorbing that suffering as well". The only resource we have to help cope with this emotional, physical and spiritual distress is ourselves.

Compassion fatigue is the convergence of primary traumatic stress, secondary traumatic stress and cumulative stress/burnout in the lives of helping professionals and other care providers. When helping others precipitates a compromise in our own well-being we are suffering from compassion fatigue.

The symptoms often mimic, to a lesser degree, those of our patients. Vicarious traumatization is a related term that also depicts this phenomenon of the transmission of traumatic stress by observation and/or "bearing witness" to the stories of traumatic events.

Secondary traumatic stress occurs when one is exposed to extreme events directly experienced by another and is overwhelmed by this secondary exposure to trauma. Several theories have been offered but none have been able to conclusively demonstrate the mechanism which accounts for the transmission of traumatic stress from one individual to another. Some hypothesize that the caregiver's empathy level with the traumatized individual plays a significant role in this transmission.

Burnout, or cumulative stress, is the state of physical, emotional, and mental exhaustion caused by a depletion of ability to cope with one's environment resultant from our responses to the on-going demand characteristics (stress) of our daily lives. High levels of cumulative stress in the

lives of caregivers negatively affect their resiliency therefore making them more susceptible to compassion fatigue.

The Silencing Response is an inability to attend to the stories/experiences of our clients and instead to redirect to material that is less distressing for the professional. This occurs when patient's experiences/stories are overwhelming, beyond our scope of comprehension and desire to know, or simply spiraling past our sense of competency. The point at which we may notice our ability to listen becoming compromised is the point at which the Silencing Response has weakened our efficiency.

ACCELERATED RECOVERY – A SAMPLE PROGRAM

Compassion Fatigue is responsive to intervention, and may even be the incentive that leads to the enhancement of care-givers skills and personal life enrichment; in the same way that a crisis may precipitate change and growth in the lives of patients.

A program that will not only address the issues of compassion fatigue for the care-giver but positively reinforce their future in their chosen role will improve their personal lives as well. The program should be designed to assist the professional to implement strategies to regain functioning in their personal and professional lives that have been compromised due to compassion fatigue. Assisting the caregiver to move toward becoming their optimal personal and professional selves so that they may live and work with integrity is the goal.

An Accelerated Recovery Program makes a commitment to assist care-givers to address and resolve both the symptoms and the cause of compassion fatigue while, at once, helping them develop an integrated individual self-care discipline which enhances future resiliency to compassion fatigue.

Caregivers may discover a need to continue their work beyond the scope of the Accelerated Recovery Program; however, they will be much better suited and prepared to manage the difficult sequel of primary and secondary traumatic stress following the completion of this program.

In addition to addressing the difficulties which are preventing the professional from performing at the optimal level, they will have the opportunity to learn, by experiential participation, state-of-the-art brief treatment procedures which they may utilize with their traumatized clients.

THE ROAD BACK HOME

The metaphor "The Road Back Home" is described because compassion fatigue seems to rob the professional of their sense of well-being, comfort, purpose, identity and empowerment; all the qualities that one associates with being "at home". The experiences of being "at home" in our bodies, our work, our thoughts and our spirit seem to diminish as the symptoms of compassion fatigue increase.

The program is created and designed with the hope of assisting helping professionals to move rapidly toward comfort and empowerment in their professional and personal lives. This program will challenge and assist the helping professional in finding their own personal “road back home”.

Treatment assists the helping professional in reconnecting with the sense of hope and empowerment with which they entered their chosen field. When this is accomplished, we encourage them to learn, understand and develop personal strategies for resolving the difficult experiences which diminish hope and empowerment.

Furthermore, the helping professional will be challenged to discover their silencing response, both with their clients and themselves, and to develop ways to navigate through this difficult impasse.

EVALUATION

A thorough assessment and evaluation is completed with each care-giver who enrolls in the accelerated recovery program. A full exploration of the symptoms that the professional is experiencing will be discussed along with the events of his/her professional and personal life which have contributed to these symptoms.

Recognize that discussion of these events will be difficult and, often times, intimidating for the professional. With this in mind, the disclosure of information is upon the professional and while you will offer the strictest confidentiality, respect any wishes that he has to not disclose any information.

The following assessment tools should be utilized in the Recovery Program:

1. Compassion Fatigue Scale-Revised
2. Silencing Response Scale
3. Solution-Focused Trauma Recovery Scale (TRS)

PERSONAL & PROFESSIONAL TIME-LINE

1. Welcome and discussion of treatment goals/mission statement
2. Categorizing these goals into the following four areas:
 - a. Skills Acquisition
 - b. Self-Care
 - c. Internal Conflicts
 - d. Connection with Others
3. Overview of program and informed consent

4. Progressive relaxation script
5. Safe-Place Visualization
6. Telling the story
7. Re-connection with hope and empowerment at beginning of career
8. Inventory of experiences which have combined to create Compassion Fatigue; review of past (week, month, year) to assess the specific situations which are triggers and catalysts of compassion fatigue.

RE-FRAMING & REPROCESSING

1. Review of Session Two
2. Discussion of Time-Line:
 - a. Professional Goals
 - b. Personal Goals
 - c. Primary & Secondary Trauma
 - d. Silencing Response
 - e. Trajectory of Hope
3. Review of vicarious traumatic situations (triggers & catalysts)
4. Review of self-regulation strategies for managing these situations
5. EMDR with Target Experience/Memory which encapsulates most salient impediment
6. Development/implementation of self-care/NAR plan
7. Letter from the Great Supervisor
 - a. Omni-benevolent
 - b. Omniscient
 - c. The things the professional most needs/wants to hear from a supervisor.

SUPERVISING THE SELF

1. Review of previous sessions
2. Identifying areas where professional needs skills acquisition and contracting to acquire these skills.
3. Identifying areas where professional needs to introduce, practice and master self-soothing boundaries / self-care

4. Video Dialogue with internal polarities/conflicts
 - a. Read Great Supervisor Letter on videotape
 - b. Video-dialogue taking the negate stance
 - c. Continue dialogue towards negotiation

CLOSURE AND AFTERCARE

1. Review of program/goals
2. Inventory of incomplete goals
3. Addressing four Pathways to Recovery
 - a. Skills Acquisition
 - b. Self-Care
 - c. Connection with Others
 - d. Internal Conflict Resolution
4. Aftercare
5. Closure

It is possible that these techniques may exacerbate and/or expose a primary trauma in the history of the helping professional. Utilize a specialized protocol of each brief procedure which, if primary traumatic stress becomes activated, will be designed to “contain” these experiences and squeal while refocusing upon Compassion Fatigue Symptom Reduction. The helping professional who experiences the emergence of primary traumatic material will be offered confidential individual treatment for these symptoms if they so choose.

OPTIONS FOR FURTHER WORK

1. All helping professionals will be offered the option of continuing individual treatment. This treatment could include:
 - a. Primary traumatic event/traumatic stress
 - b. Secondary traumatic stress
 - c. Grief work
 - d. Problematic clients/therapeutic impasse
 - e. Personal blockages/inhibitions
 - f. Phobias
 - g. Stress reduction/management
2. All individual treatment will attempt to employ brief treatment protocols (where applicable)
3. Groups may be offered

4. Training/consultation in treating traumatic stress may be offered
5. Assistance in establishing study groups/peer supervision
6. Opportunity for membership in Green Cross Project
7. Membership in Traumatic Stress E-Mail Forum

BURNOUT

Burnout is “a syndrome of emotional exhaustion, depersonalization, and reduced personal accomplishment that can occur among individuals who do 'people work' of some kind. Burnout is a depletion of energy and a feeling of being overwhelmed by others' problems.” The word, as it is listed in Webster's New International Dictionary, has three examples for its use:

The burning out of the interior or contents of something, such as a building. You can probably visualize yourself being devoured from within by your fiery expenditure of energy until you have nothing left.

The breakdown of an electrical circuit owing to combustion caused by high temperatures. In this case, the high temperature produced by the electrical current burns out a conductor. Again, in application to yourself, your emotional energy supply becomes completely short-circuited due to the over-heating of constant stress.

The severe denuding of the forest floor as a result of a forest fire. Your resources to rejuvenate yourself have been utterly consumed by the stressful burdens so that renewal seems hopelessly difficult.

More specifically, burnout is associated with myriad sources of stress and hassles involved with your work (tensions with supervisors, work schedules, co-workers, paper work, equipment malfunctions, the bureaucratic system, etc.), and is a state of extreme dissatisfaction with your work as you work too long, too hard and under too much pressure. Burnout results in a loss of enthusiasm, energy, idealism, perspective and purpose on a mental, physical, emotional and spiritual level.

Burnout happens when helpers/caregivers become extremely dissatisfied with their work and become cynical, depressed, emotionally exhausted, irritable with supporters, and even impaired. Burnout requires professional help and discontinuing being a caregiver until the cynicism and impairment are gone.

SYMPTOMS OF BURNOUT

Physical Indications of Burnout

- A persistent sense of physical fatigue: feeling “run down” and exhausted and “keeping up to speed” becomes increasingly difficult
- Frequent headaches, migraines
- Chronic muscle tensions, especially of the head, necks and/or lower back
- Gastrointestinal problems (ulcers)
- Decreased appetite (or a never-satisfied appetite)
- Sleeplessness in spite of feeling fatigued
- High blood pressure
- Shortness of breath
- Nervous tics, tremors, teeth/jaw clenching

Psychological Indications of Burnout

- Depression (“I don't care anymore!”)
- A dulling affect, mental fatigue (“I can't think straight anymore!”)
- Increased irritability, hostility (“I hate this job now!”)
- Decreased tolerance for frustration (“I can't take it anymore!”)
- Feelings of helplessness and an inability to see a way out of problems (“I dread going to work!”)
- Increased risk taking and impulsivity
- Inflexibility of behavior and goals (“I can't adjust to this!”)
- Cynicism and negativism about self, others, work and the world in general (“I can't stand this anymore!”)
- Apathy (“I don't care anymore!”)
- Reduction and/or abandonment of recreational activities (“I'd rather stay home now!”).
- Decreased capacity for pleasure and social contacts (“I don't want to go out anymore!”).
- Withdrawal, detachment (“I'd rather be alone!”).
- Increased interpersonal and/or marital discord.

Spiritual Indications of Burnout:

- Disillusionment and disappointment with God
- You feel that God is powerless to help
- You feel that God does not care
- You feel that God has abandoned you, your and the family
- Discontinuance of religious practices
- You stop worshipping – privately and corporately
- You stop praying
- You stop reading your Bible
- Development of spiritual apathy

Performance Indications of Burnout:

- Decreased efficiency

- Diminished initiative
- Reduced interest in work (as well as a general apathy)
- Depleted ability to work under stress
- Difficulty concentrating or paying attention
- Increased irritation with colleagues
- Increased use of tranquilizers, alcohol, cigarettes

CAUSES OF BURNOUT

The personality traits of the individual who is likely to develop burnout may embrace:

- Someone highly task and goal oriented
- A person who takes particular satisfaction in doing things neat and orderly (i.e., a perfectionist)
- Someone with a high need for achieving “control” of self, others and/or the environment; is intensely competitive
- An individual who tends to be overly critical but cannot stand criticism
- Someone with a marked capacity to delay gratification (or perhaps an inability to allow personal satisfaction)
- A person with excessively high personal expectations and exaggerated expectations of others
- Someone whose work and “productive” activity is overvalued and provides the major source of self-esteem and pleasure (doing is the key to being worthwhile)
- An individual with a scarcity of non-work related interests in the form of recreation and hobbies

WARNING SIGNS OF BURNOUT

Just as meteorologists can recognize certain signs as warnings of an approaching hurricane, so psychologists can recognize symptoms of approaching burnout.

Exhaustion

A lack of energy associated with feelings of tiredness and trouble keeping up with one's usual activities.

Detachment

Putting distance between you and other people, particularly those with whom you have close relationships.

Boredom and Cynicism

You begin to question the value of friendships and activities – even of life itself.

Increased Impatience and Irritability

As burnout takes hold, your ability to accomplish things diminishes and your impatience grows and causes flare-ups with others.

A Sense of Omnipotence

You have thoughts such as “Nobody can do my job better than I can.”

Feelings of Being Unappreciated

Burnout victims experience complex feelings of bitterness, anger, and resentment because they are not being appreciated more for their added efforts.

Change of Work-Style

Reduced results and conflicts with colleagues will eventually cause you to either withdraw from decisive leadership and work habits, or you will seek to compensate for the conflicts by becoming more tyrannical, demanding and inflexible.

Paranoia

Once burnout has taken a long-term hold, it's a small step from feeling unappreciated to feeling mistreated and threatened.

Disorientation

Long-term burnout increases difficulty with wandering thought processes.

Psychosomatic Complaints

Headaches, lingering colds, backaches, and similar complaints are often a result of the burnout victim's emotional stress.

Depression

In burnout, the depression is usually temporary, specific and localized, pertaining more or less to one area of your life.

Major Depression

This state is usually prolonged and pervades all areas of your life.

Suicidal Thinking

As the depression progresses, the result can be suicidal thoughts.

IMPLICATIONS OF BURNOUT AND COMPASSION FATIGUE

Without a “pressure release valve,” the holding tank will ultimately explode when the pressure gets too great. Can you feel the strain of the pressure building up inside you from your care-giving? If so, when and how will you release the pressure?

Without “recharging the battery” after continuous use, it will surely go dead and become useless. Can you sense that you are running low on physical, emotional and spiritual energy? If so, when and in what ways will you recharge yourself?

Without “changing the oil” in the car, damage will eventually be done to the engine the longer you drive it without maintenance. Can you feel the wear and tear of the many miles you have put on yourself at work? If so, when and how are you going to schedule some routine maintenance on your life?

“Overloading the system” will inevitably lead to a serious breakdown. As a caregiver, can you feel the weight bearing down upon you, overloading your physical, emotional and spiritual systems? If so, when and in what ways are you going to lighten / balance the load?

RESOLVING BURNOUT: COUNTERING THE BURDEN

AN OLD TESTAMENT EXAMPLE – ELIJAH (1 KINGS 18-19)

THE AGGRAVATION

Burnout frequently occurs after intense “peak” experiences, such as Elijah's “mountain top” victory (1 Kings 18). Elijah had recently experienced the greatest success of his career: the ending of a famine, a revival among the people, the priests of Baal killed and his credibility restored. Then we see the despondency that can often follow prolonged intensity (1 Kings 19). Elijah demonstrates a classic example:

It's the letdown that comes in between crises or directly after “mission accomplished.” Frequently, following a triumph, high achievers (Elijah certainly qualifies) suffer periods of deep melancholia akin to the postpartum depression some women experience after giving birth. The feelings are remarkably similar: sadness, separation, sluggishness, and above all, emptiness.

Other stress-related characteristics Elijah exhibited during his burnout were:

- Rejection (v. 2)
- Detachment (he ran away from everyone, v. 3)
- Exhaustion (physically, v. 5-6, mentally, emotionally and spiritually)
- Suicidal thoughts (an advanced stage of the depression and despair that result from burnout, v. 4)
- Bitterness (he reminded God how zealous he had been, v. 10)
- Feelings of being indispensable (v. 10)
- Feelings of being mistreated (v. 10)
- Feelings of self-pity (v. 10)
- Feelings of persecution (he felt put upon and became increasingly suspicious of his environment)

THE ADAPTATION

We can learn much from what God did to minister to His servant's physical, emotional and spiritual needs during this time of compassion fatigue. Therapy came in the form of God's presence, His loving patience and His purposeful assignment. And Elijah was fully restored!

- God provided time for sufficient rest and proper nourishment (v. 5-6).
- God offered a “quiet time” for Elijah (v. 12).
- God provided a sense of companionship (v. 18).
- God gave him an assignment that he was capable of fulfilling (v. 16).

THE APPLICATION

Opening ourselves to God, our personal Counselor, can also change our perspective of our pressure. He does understand what we are going through. Hear His words of comfort through the pen of the Psalmist:

*In my anguish I cried to the Lord, and He answered by setting me free.
The Lord is with me; I will not be afraid.
What can man do to me?
The Lord is with me; He is my helper.
I will look in triumph on my enemies.
It is better to take refuge in the Lord than to trust in man.
It is better to take refuge in the Lord than to trust in princes. (Psalm 118:5-9)*

A NEW TESTAMENT EXAMPLE – JESUS (MARK 6:7, 12-13, 30-32)

Jesus recognized that the stresses of life can lead to physical, emotional and spiritual symptoms of burnout; and he recognized that these stress levels need to be lightened so that recovery can begin. It is so easy to become so concerned with “getting the job done” that we lose sight of the needs of the people who are actually carrying on the work. A close examination of His brief statement shows there are three key elements that can relieve the stresses that lead to burnout.

- A change in location – to experience peace and quiet.
- A change in activity or responsibility – to rest up.
- A certain amount of time – to take a break for a planned amount of time.

In applying this example to your own life, consider the following:

- Know your own “triggers” and vulnerable areas and learn to defuse them or avoid them.
- Resolve your own personal issues and continue to monitor your own reactions to other's pain.

- Be human and allow yourself to grieve when bad things happen to others.
- Develop realistic expectations about the rewards as well as limitations of being a helper.
- Set and follow appropriate limits and boundaries for yourself and tell them to others.

PHYSICAL RENEWAL

THROUGH EXERTION

Because ministry is normally a sedentary profession, you need to adopt a thirty to sixty minute program of regular (at least three times per week) physical activity – in the form of jogging, walking, bicycling, swimming, tennis, racquetball, basketball, working out at the local spa – anything, as long as you find the exercise interesting and it is strenuous enough to produce deep breathing and liberal perspiration.

Be sure to consult with your physician for his recommendation of a safe level of exercise for you – especially if you are over forty years old or have any health complications.

THROUGH NUTRITION

You need to regularly eat a well-balanced diet when under a lot of pressure. Most nutritionists agree that the best diet is a balanced one that includes some of all the food groups. Foods you might want to limit when experiencing stress:

- Reduce the amount of caffeine-rich beverages you consume (e.g., coffee, colas, tea and cocoa).
- Decrease your intake of fat and sugar. It has been said that, “Our reserves in physical energy disappear proportionately as our waistline expands.”
- Get enough fluids into your system throughout each day. The universal recommendation is six to eight glasses of water a day.

THROUGH RELAXATION

To sleep soundly for a full night is a valuable restorative gift. Proper rest allows your physical, mental and emotional self to regain lost energy. Rest restores us. Determine how much sleep you need to feel and function at your best (Most studies show that most adults need about eight hours per night.) and then determine to get it most nights during the week.

You need to take appropriate breaks daily – not working for too long a period of time and not working on one situation for too long. You need weekly breaks – not working over fifty hours a week. You need to take a quarterly long weekend off and a yearly break of at least two weeks off.

WITHOUT ADDICTION

You must avoid using drugs and alcohol to help you cope with stress. Tranquilizers and sleeping pills should be used only under a doctor's care and with extreme caution.

Drugs and alcohol merely numb the symptoms of the stress. They do nothing to help cure the cause. In fact, alcohol can actually cause stress. In laboratory tests, alcohol has been shown to trigger the release of stress hormones from the brain and pituitary and adrenal glands (the same reaction that might be brought on by money woes or marital problems).

EMOTIONAL RENEWAL

A common ingredient among people who experience burnout is the fact that they do not have a friend to whom they are close enough to share their personal feelings and still feel loved and accepted. Studies show that people with social networks handle crises better.

You need to cultivate a confidant with whom you can openly and honestly discuss what is going on in your heart and mind. The very worst way to deal with burnout is to bury it inside. The lack of a feedback system is not a sign of strength, but a sign of being foolish.

You need someone to listen attentively while you share your concerns and heartaches and who can honestly respond to you with supportive comfort and counsel. Regularly discussing your frustrations and fears with someone you trust can provide substantial relief from pressure – even if it seems that at times nothing at all can help. Simply being able to put words to your feelings in the presence of a supportive person can be very freeing; it can even reenergize you.

THROUGH LAUGHING

A wise man once compared a cheerful heart to good medicine (Proverbs 17:22). Humor, if you use it well, can be one of the most helpful things you can do to relieve tension; being able to laugh about something often helps to put it into proper perspective. Ask yourself: “Have I laughed several times today?” If not, then do something to make yourself laugh: read a joke book, watch a comedy, look at old photos; whatever, as long as it will make you smile. Enjoy life!

THROUGH SUPPORT

Find opportunities to acknowledge, to express and to work through your experiences in a supportive environment. Seek assistance from other colleagues and caregivers who have worked in a similar environment and have remained healthy and hopeful. Develop a healthy support system to protect you from compassion fatigue and emotional exhaustion.

JOURNAL WRITING

Personal journal writing is a consummate prescription for self-discovery, problem solving and healing emotional wounds. Our inner world may be clarified, calmed and comforted by revealing our feelings on paper (or a word processor).

SPIRITUAL RENEWAL

Your spirituality – your sense of belonging to God completely and of God's abundant life in you – is, in my opinion, the most important element in coping with stress in your life. And Dr. Frederick Flack, in his book, *Resilience: Discovering a New Strength at Times of Stress*, agrees: “I believe the most vital ingredient of resilience is faith.”

In the words of David A. Ruch, M.Div., M.A., a licensed clinical professional counselor: “Our limitations as healers should draw us constantly back to dependency on God, not only for power and faith to continue but for comfort and perspective when we feel defeated. When we recalibrate ourselves based on his sovereignty rather than our circumstances, we have new hope.”

THROUGH ADORATION

There is something uplifting and rejuvenating from spending time in praise and worship with a group of people who share your beliefs.

There is therapeutic power for physical, emotional and spiritual renewal in listening to and singing inspirational music. For example, a hymn based on an early Greek hymn that dates as far back as the eighth century encourages us with these words:

*Art thou weary, art thou languid,
Art thou sore distressed?
“Come to me,” saith One, “And coming
Be at rest.”
Hath He marks to lead me to Him,
If He be my Guide?
In His feet and hands are wound-prints,
And His side.
Finding, following, keeping, struggling,
Is He sure to bless?
Saints, apostles, prophets, martyrs,
Answer, “Yes.”*

When pressing situations are upon you, you need to take time out to get spiritually oriented in order to refocus your attention on the “Problem Solver” who is greater than any of your pressures.

Worship is one way to experience a rejuvenating supply of wisdom and strength and peace from God. Come to Him and unload your cares. He can handle it.

THROUGH EDUCATION

Read an inspirational book. Stimulate your soul as you gain understanding, find encouragement and revitalize your hope through the experiences and lessons of others.

Read a devotional book. Acquaint yourself with your spiritual source of hope and renew your faith, through the reading of the Scriptures associated with your belief system. Meditating on the Word of God allows God to speak to us personally through the words that apply, in one way or another, to all of us.

The words in Isaiah 40:27-31 or Lamentations 3:17-26 or Matthew 11:28-30 are especially good to read when you feel weary and faint from the burdens pressing down upon you. You can experience hope and renewal when your attention is focused beyond your circumstances to the all-sufficient character of the eternal, faithful, all-powerful, ever-present, gracious Creator.

THROUGH MEDITATION

Prayer is the spontaneous, heartfelt sharing by needy human beings with God, who is able and willing to help. Bringing your pressures to God can change your perspective – it can keep you from becoming myopic – and help you to cope. Through prayer and meditation you can sweep the mind of all turmoil.

In place of our exhaustion and spiritual fatigue, God will give us rest. All He asks is that you spend time with Him, meditating on Him, talking to Him, listening in silence, occupying yourselves with Him (Hebrews 12:3).

THROUGH ABSOLUTION

Confession

Ignoring transgression (when you have “crossed the line”) in your life will tend to place a great emotional, spiritual and physical burden on yourself. God's forgiveness is always sufficient and immediately available (1 John 1:9). He welcomes repentance with open arms.

Forgiveness

If you do not forgive others, you will tend to turn your anger inward, which results in bitterness, and then depression, and finally you will experience burnout symptoms. Forgiveness involves an act of the will – it is choosing to no longer hold a grudge against an offending party. Freedom from bitterness (through forgiveness) is necessary for effective recovery from burnout.

DIVERSIONAL RENEWAL

THROUGH RELAXATION

Maintaining good mental health often involves learning to relax. There are many books, tapes and seminars that can help teach you personal techniques on learning to mentally and physically relax yourself. When the sympathetic nervous system is quieted by these practices, muscle tension decreases, the heart rate slows and a feeling of well being often occurs.

Here is one progressive muscle relaxation method: Isolate yourself from all noises and distractions (like the phone, TV, etc.), sit in a comfortable chair with your feet flat on the floor (or, if you are in a recliner chair, resting comfortably on the footrest) and your hands resting comfortably in your lap or upon the armrests. Close your eyes. Make a deliberate effort to relax all your muscles.

Begin with your head, then relax all your neck and back muscles. Let your chest and stomach muscles release their tension. Feel your arms becoming limp. Allow your legs and feet to completely relax. Spend about ten to fifteen minutes relaxing all your muscles as you feel the tension drain from your body.

THROUGH RECREATION

Have a life beyond your professional work that nurtures you personally. Leisure is free activity, whereas labor is compulsory activity. In leisure you do what you like, but in labor you do what you must. In your labor you meet the objective needs and demands of others, but in leisure you scratch the subjective itches within yourself.

Some recommend engaging in some form of enjoyable recreation (leisure time) at least three times per week – something not connected with your usual line of work. Watching make-believe characters on TV is never a substitute for experiencing life yourself.

Take Mini-Vacations: If you are “vacating” only once a year (like many people), that block of time almost suffocates in the desperate attempt to cram a whole year's worth of happy escape into two weeks. You would fare much better to plan more consistent and more frequent breaks, each with a different purpose, to meet the various needs of your family. You need to break the habit of looking in the TV guide for your happiness each weekend.

During your lunch break (a respite time) you might include: going on a picnic, going for a walk around the block, buying some flowers for the desk, or reading from a good book. **After dinner** you might consider: playing a table game, singing a song together as a family, doing finger painting together, going swinging in the park, or watching the sunset from a hill top.

ORGANIZATIONAL RENEWAL

THROUGH POSITION

What are your priorities? You must try and keep a tight rein on your priorities, especially at times of greatest anticipated stress. You are likely to be an over-estimator as to what you can realistically do. You probably find it difficult to say “No” (both to yourself and others who may place demands on you). You must be rigorous in your assessment of priorities concerning meeting the needs of others.

You need to practice saying no to activities of lesser priority – regardless of how worthwhile they may seem. Think about the idea that if you never say “no”, what is your “yes” worth?

Set and keep healthy boundaries for work. Ask yourself, “Will the world fall apart if I step away from my ministry for a day (or a week)?”

THROUGH INTENTION

What is your plan for using your time wisely? Organizing your life may appear like a tall order with which you have difficulty at times, but you can learn to plan ahead. When you know what needs to be done, you are not as prone to experience surprises in your life. If emergencies do arise, then they are easier to cope with. While it is not necessary to become a slave to a schedule, getting organized can help you run your life more smoothly and efficiently.

Part of organizing your life involves planning “time outs” or mini-vacations. This is necessary for your survival. Consider creating small “buffer zones” between some of your obligations to allow yourself ten to fifteen minutes to close your eyes, pray, reorient your priorities and defuse your tension.

Time can work for or against you, depending on how you choose to use it. You can allow yourself to procrastinate and then rush to meet deadlines, you can leave little time to finish projects and you can hurry from one activity to another without taking a moment to catch your breath or utter a prayer. But, when you organize your time by setting priorities and planning accordingly, you stay directed and live a purposeful life that is much less stress-filled.

NOTES

Module 9
Hospice Manual
Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. Explain compassion fatigue in your own words and discuss why it is dangerous for chaplains.
2. List 6 symptoms of compassion fatigue and explain why they would be problematic in your day to day role as a chaplain.
3. What is the difference between burnout and compassion fatigue?
4. Give a biblical example for fighting burnout and relate it to your own situation.

MODULE 10: SELF CARE

CAREGIVER SUPPORT

Being a caregiver can be exhausting – both physically and emotionally. Many caregivers find it much easier to focus on their loved one's needs, and neglect their own.

Regardless of age, sex, race and ethnicity, caregivers report the following health concerns:

- Exhaustion
- Poor eating habits
- Failure to exercise
- Postponing or missing medical appointments
- Anxiety
- Stress
- Isolation
- Depression
- Frustration

Additionally, caregivers are at increased risk for excessive use of alcohol, tobacco, and other drugs. Studies show that an estimated 46 to 59 percent of caregivers are clinically depressed.

If you are a caregiver, it is essential to find the time and resources to take care of your own health. Taking care of yourself first is the only way you can continue to effectively care for your loved one.

Remember, giving your all does not mean giving up your own health and well-being. You can develop skills for coping with the challenges of being a caregiver.

Here are some suggestions you may find helpful:

- Identify sources of stress.
- Get the food and rest you need.
- Take time for yourself.
- Let others take part in the work of care-giving.
- Seek and accept support for yourself.
- Watch out for destructive ways of coping.

Identify sources of stress.

You probably cannot change a family member who has always been demanding or stubborn, but you can control how you respond to the demands. Small changes can make a big difference. Sometimes letting go of unrealistic expectations or adjusting your standards of how frequently or how well you perform a task (such as housekeeping) will make a significant difference.

Get the food and rest you need.

Make yourself sit down and eat three meals a day. It is easy to ignore your own need for nourishment when you are busy and under stress. If your sleep at night is disturbed by giving care, take a nap during the day while your loved one rests. Try to find someone who will provide occasional or even regular nighttime care.

Take time for yourself.

Let yourself be alone for a short time to clear your head. Hospice volunteers can be used to provide respite care so that you can take a much-needed break. Get out for a breath of fresh air or a change of scenery; even a brief walk can make a difference.

Exercise has many benefits; it promotes better sleep, reduces tension and depression, lifts spirits, and increases energy. Think of ways you can fit exercise into your daily routine. Relax in a warm bathtub, read a book, or listen to music. Go to a movie or have lunch with a friend.

Let others take part in the work of care-giving.

Learn to accept and ask for help, especially from family, friends, and community. This will help you; plus, others won't feel so powerless when they feel included by doing something – anything – to help.

Make a list of tasks and put them in order, according to what is important for you to be involved in, versus things you can ask someone else to do. Then you can offer specific ways that others can help: making meals, running errands, sitting with your loved one, or taking the children out.

Seek and accept support for yourself.

Talk to friends and family about your feelings. All feelings are legitimate, even those that upset you (anger, sadness, guilt). It is healthy to cry and express emotions. A support group can help relieve tension, give a new perspective on the situation, increase understanding, and build support. Some groups are oriented to specific diseases like cancer, Parkinson's disease, or Alzheimer's disease.

Find ways to care for your spiritual self. Whether or not you are affiliated with a particular religion, seeking guidance from someone who shares your spiritual outlook can help. Hospice chaplains are available to provide spiritual support.

Watch out for destructive ways of coping.

These include drinking too much, misusing medications, and overeating. Seek medical advice if you experience changes in your health such as stomach ailments or high blood pressure.

COMPASSION FATIGUE

When chaplains suffer from compassion fatigue, a deep physical, emotional and spiritual exhaustion accompanied by acute emotional pain occurs. Whereas chaplains with burnout adapt to their exhaustion by becoming less empathetic and more withdrawn, compassion-fatigued

chaplains continue to give themselves fully to their patients, finding it difficult to maintain a healthy balance of empathy and objectivity.

Those who have experienced compassion fatigue describe it as being sucked into a vortex that pulls them slowly downward. They have no idea how to stop the downward spiral, so they do what they've done all along; they work harder and continue to give to others until they're completely tapped out.

COMPASSION FATIGUE IS FLOURISHING

Compassion fatigue is flourishing today, due in part to the demands of chaplain care. Chaplains see more death and dying, do more visits, negotiate more contracts and have less autonomy than ever before. Add to that self-imposed pressure to live up to individual high standards, and it's no wonder many chaplains feel like they're going up in flames.

The hospice chaplain profession, with its tremendous physical and emotional demands, naturally predisposes chaplains to compassion fatigue. In the past, the connection that many chaplains shared with their contacts gave them the replenishment they needed to cope with the stressors of practicing spiritual medicine. But today, increasing demands have caused some chaplains to stop taking the time to appreciate the love, respect and appreciation that their patients want to share with them.

TIME IS THE ENEMY

To those who are in the throes of compassion fatigue, time, or more precisely the lack of it, is the enemy. To compensate, many chaplains try to do several things at once (e.g., eat lunch while returning telephone calls and taking care of business). And to make more time, they tend to eliminate the very things that would help revitalize them: regular exercise, interests outside of medicine, relaxed meals, time with family and friends, prayer and meditation.

At this point, they find it easiest to blame others. "If only," they lament. If only the family, nursing staff, or their colleagues did things differently, they'd have more time. And, no matter how much or how well they sleep, they still awaken exhausted.

To prevent or recover from compassion fatigue, take time for self-reflection, identify what's important and live in a way that reflects it. To sustain yourself at work, develop "principles of practice" – guidelines of personal integrity that articulate the parameters of your personal values. Commit to live and work within these principles.

Hard data on compassion fatigue is admittedly difficult to come by; however, one survey found that 54 percent of chaplains had experienced a time when they felt they no longer had any compassion left to give, even after a restful weekend.

THERE IS HOPE

If you see that you are suffering from compassion fatigue, don't worry. Relief is actually nearby. To recharge your batteries you must first learn to recognize when you're wearing down and then get into the habit of doing something every day that will replenish you. That's not as easy as it sounds. Old habits are oddly comfortable even when they're bad for us, and real lifestyle changes take time, energy and desire.

The first step toward overcoming compassion fatigue is to learn how to take care of yourself. Because chaplains with severe compassion fatigue have to learn or re-establish lifestyle habits that increase their emotional resilience, they are encouraged to take time off if possible.

During the time off, start exercising and began eliminating the junk food. Spend time with friends and family and reconnect with the world. Start projects or hobbies. Meditate on biblical studies that will reinstate the reassurance that you are where you are supposed to be.

Overcoming compassion fatigue means coming to terms with the anger, fear and self-doubt that some chaplains have suppressed since beginning their profession as a hospice chaplain. This requires honest self-reflection, a process that some chaplains find quite painful. Yet, if you're compassion fatigued, getting back in touch with yourself is perhaps the most important step in the recovery process. Without it, the lifestyle changes you're trying to make may not be enough to sustain you.

It helps to have someone to talk to who is a good listener, understands compassion fatigue, and with whom you feel a connection. This person is usually a professional counselor, but a colleague with firsthand knowledge of compassion fatigue, a pastor, or a spouse or friend who can listen without judging or offering solutions to your problems are other alternatives.

A well-facilitated chaplain support group, although sometimes difficult to find, is also an immensely safe place. Colleagues who have learned to listen deeply can offer you caring and innovative options based on their own experiences.

If you're like most chaplains, your personal identity is closely tied to your professional role. Try not to attribute compassion fatigue to a character flaw. Negative self-talk about “not having what it takes” serves no one – not you, not your family, not colleagues or patients, and most certainly not nursing staff members, who may have already received a fair share of your irritability. Finally, understand that the pain of compassion fatigue is uncomfortable but normal, and that it will dissipate once you start caring for your physical and emotional needs.

DEVELOP YOUR OWN SELF-CARE PLAN

The lifestyle changes you choose to make will depend on your unique circumstances, but three things can speed your recovery.

1. **Spend plenty of quiet time alone.** Learning mindfulness meditation is an excellent way to ground yourself in the moment and keep your thoughts from pulling you in different directions. The ability to reconnect with a spiritual source will also help you achieve inner balance and can produce an almost miraculous turnaround, even when your world seems its blackest.

2. **Recharge your batteries daily.** Something as simple as committing to eat better, and stopping all other activities while eating, can have an exponential benefit on both your psyche and your physical body. A regular exercise regimen can reduce stress, help you achieve outer balance and re-energize you for time with family and friends.

3. **Hold one focused connected and meaningful conversation each day.** This will jump start even the most depleted batteries. Time with family and close friends feeds the soul like nothing else and sadly seems to be the first thing to go when time is scarce.

WORDS OF ADVICE

Compassion fatigue can impair your functioning in ways that you need to keep in mind, so it comes with its own list of “don'ts”:

Don't make big decisions. You should not make any major life decisions until you've recovered physically, emotionally and spiritually. This is perhaps the most important advice I can give.

Don't quit your job, obtain a divorce, have an affair or spend your money on a lavish trip or a new sports car. It may feel great at the time, but a few days or weeks later you'll find yourself waking up to the same set of problems. Chaplains tend to eliminate the very things that would revitalize them.

SPIRITUALLY OVERCOMING COMPASSION FATIGUE

The first thing that everyone normally attempts is getting away from work for awhile. You can do something as simple as take time off but the question is how long do you stay charged? For how long does the vacation alleviate your compassion fatigue? Does the relief last for years?

The research indicates that the beneficial effects of some respite from work will fade very quickly. In particular, best estimates show that relief from compassion fatigue and job stress in general begins to wane after a mere three days back at work. By day 21, whatever relief we experienced is expected to be gone completely! Not good news for someone trying to remain merciful.

Besides time off, the other “solutions” advanced by business scholars generally revolve around addressing the causes of compassion fatigue listed earlier (e.g., reduction in your workload, get another boss, get another job). The problem with these approaches is that we have no real evidence that any of these things actually works in the long-term either. Before we know it, the fatigue problems of the old situation may resurface in the new one; square-one syndrome.

It's not hopeless, though. Often, it seems that Scripture goes where academic research cannot. This is a classic case. If you want a lasting solution for your compassion fatigue, if you want to overcome your weariness for caring about others, don't just look to vacations, to weekends, or to a new job to renew you. Look to God to renew you.

In Isaiah we read that God “gives strength to the weary and increases the power of the weak. Even youths grow tired and weary, and young men stumble and fall; but those who hope in the Lord will renew their strength...” (Isaiah 40: 29-31a). It's a timeless message. Isaiah underscores a pervasive Biblical theme: when you are fatigued, when you don't care, when you feel like you can't give anymore than you're already giving, stop and ask God for help. Don't try to do it alone. God has endless strength, you don't. So ask Him for the sensitivity to care. Do you really think that He'll deny that sort of request? Do you really think He'd send His Son to teach: “Blessed are the merciful” and then ignore us when we ask for a more merciful heart?

He won't. The solution for compassion fatigue, the only solution whose effects will not fade after three days or three weeks, is to regularly tap into the power of the Holy Spirit. Pray regularly that He will work through you on the job. Pray daily for those around you at work. Pray that you'll continue to care about them. Pray for the discernment to identify their pain. And pray for the energy and the wisdom to attend to it.

That prayer doesn't take much time each morning. “Lord, help me to care about the people around me at work today. Give me a merciful heart.” You may even find the time to pray that two or three times in your workday. Devote more if you can, but a few sincere seconds, when practiced habitually, is really all that it takes. No fancy research conclusions. No large-sample studies or correlation tables; just God's empowerment.

That's not to say that the time off recommended by these studies is unnecessary. It's both deserved and healthy. (Let's give credit where it's due, though. It was God Himself who came up with that innovation: “Six days you shall labor and do all of your work, but the seventh day is a Sabbath to the Lord your God. On it, you shall not do any work;” (Ex. 20:8) But it is to say that a cure for compassion fatigue is available regardless of how many vacation days you have left.

The hallmark of a Christian is care, mercy, compassion. There's a lot at stake here – and not just for others. Without mercy, Christ-likeness is impossible. With it, it's inevitable.

There many identified causes of compassion fatigue and many different means of cure. Critical Incident Stress Management (CISM), Critical Incident Stress Debriefing (CISD), medication and Eye Movement Desensitization and Reprocessing (EMDR) which is a method of psychotherapy that has been extensively researched and proven effective for the treatment of trauma, are just some of the techniques used to combat compassion fatigue.

CISM - CRITICAL INCIDENT STRESS MANAGEMENT

The “classic” CISM model was developed by Dr. Jeffrey Mitchell of the University of Maryland for use with emergency services personnel and promulgated by the American Critical Incident

Stress Foundation, which was founded in 1989 (the name was changed to the “International Critical Incident Stress Foundation” in 1991 to reflect the expansion of the model beyond US boundaries).

Initially developed for firefighters, paramedics and police officers, the use of the Mitchell Model has been expanded for use in natural disasters, school-based incidents, and a variety of other settings, including, in recent years, the U.S. military and survivors of terrorist acts.

Critical Incident Stress Management (CISM) is an integrated system of interventions designed to prevent and/or mitigate the adverse psychological reactions often accompanying death, dying, disaster, burnout, or other response emotional reactions.

The CISM process is not therapy; its goal is to return the affected group or individual to their normal level of functioning. CISM concentrates on mitigating post-traumatic stress reactions. CISM has proved a means to assist personnel in dealing with the symptoms of Critical Incident Stress.

The intervention process involves trained peers with oversight from experienced mental health professionals with advanced training.

Every chaplain should know and understand what CISM is and when it is used for self-help and for the help of emergency workers, hospital workers and the family of those involved with death and dying.

The chaplain should also know how to set up a CISM team for use in emergency situations. This segment explains how to do that.

Stress Management – Your Web of Support

Our friends and family generally form a nice web of support that makes the day-to-day hassles and occasional crises more palatable. They can be counted on to:

- Help put things in perspective
- Point out the big “rocks”
- Make us laugh
- Bring us warm fuzzies
- Care about us even when we are crabby
- Give us space when we need it
- Research tells us that people who are connected to someone (church, friends, family, and support groups) live longer and are healthier.

One of the challenges of being a Hospice Chaplain and dealing with difficult situations is not being able to talk about it with our family and friends because of confidentiality. In addition, most people don’t really understand the kind of stress that we are confronted with.

It's important to remember that although we cannot talk about the specifics, we can: Give ourselves permission to feel badly and share our feelings with others. Talking is a healing medicine.

Our families and friends can't read our minds, although they can tell when something is wrong. Let them know what would be helpful to you; including saying "I just need you to listen." Spend time with others. Immersing yourselves in the present moment can be deeply satisfying. It doesn't take away the stress but it does lessen the impact on you.

Finally, don't forget to talk to yourself in a kind and caring manner. Our self-talk frequently focuses on the negative, which tends to increase our stress and fatigue. Be aware of what you are saying to yourself and challenge yourself to focus on something positive. If you cannot find anything positive at least keep the self-talk on neutral ground.

WHAT IS A CRITICAL INCIDENT?

A Critical Incident is defined here as an event which is extraordinary in nature; with the expectation of producing significant reactions on the part of victims or those either directly or indirectly impacted.

Emergency response personnel as well as chaplains who work in areas such as Hospice operate under a variety of stressors: the uncertainty of the next call, the human tragedies involved, the hazards associated with the call, and the fear of doing something wrong.

Most often we can cope with these stressors and consider them as "part of the job." Some situations, however, cause lasting impressions which can challenge our ability to function on the job and at home. It is these situations, which produce the unusually strong emotional reactions, which are referred to as critical incidents.

It can be:

- An expected death
- A sudden death or serious injury
- A prolonged incident (aftermath of natural disaster)
- Knowing the victim or family
- An injury or death of co-worker
- Robberies
- Auto accidents
- Client illness (heart attack in lobby)
- Severe or prolonged illness of employee (Cancer, AIDS, etc)
- Death or dying
- Children's death or serious injury
- Multiple fatalities or seriously injured survivors
- Suicide, successful or attempted
- Natural disasters
- Acts of violence resulting in injury or even death

- Observing any traumatic event

“There is no training in the world, no person in the world who can stand the constant bombardment of human misery without help.”

HOW CAN A CRITICAL INCIDENT AFFECT ME?

Normal symptoms following one of these incidents can include preoccupation, insomnia, and loss of appetite, difficulty in concentration, and flashbacks, or feelings such as guilt, hopelessness, anxiety, or simply helplessness. Although these reactions are considered normal, they can have a serious effect on physical and emotional well-being.

WHO CAN USE THIS PROGRAM?

CISM services are available free to first responders, Hospice workers, emergency services personnel, hospital staff, and other members of the response systems.

Critical incidents that cause one provider to suffer the impacts of stress may have little to no effect on others. Confidential one-on-one support service is also available through the CISM program.

The purpose of critical incident stress management (CISM) is to assist those affected by any traumatic event to cope with stress effectively. CISM includes pre-incident training and post-incident services to help those who have suffered a catastrophic or traumatic experience, or for those who deal with death and dying.

Because CISM promotes mental health and well being, Chaplains in every walk of life should be familiar with CISM, the training requirements, and the procedures to request support when necessary.

Chaplains are responsible for the well being of assigned personnel in hospice care. They are required to perform their duties in harsh environments and in the face of great human tragedy and suffering. Chaplains may experience stress, frustration, and empathy with those involved in a traumatic incidents or during death. The chaplain should never discount those individual affected or repress individuals' responses to these incidents.

A strategy implying “You'll get used to it” or “It comes with the job” is ineffective to help members cope and leads to burnout, Post-Traumatic Stress Disorder (PTSD), substance abuse, or other personal and mental health problems.

CISM TEAMS

TRAINING REQUIREMENTS

CISM teams shall be certified by any accredited training source that provides training for responders responding to critical incidents.

COMPOSITION

CISM teams shall consist of:

Team Coordinator: This position normally shall be an employee such as the Hospice coordinator assigned to the Staff at the servicing department or facility.

Mental Health Professional: This team member shall be a psychiatrist, psychologist, social worker, or other licensed mental health professional who has attended either the basic or advanced ICISF courses for CISM.

Chaplain: The Chaplain, in listening to and guiding participants, shall appropriately bring to bear a moral and spiritual perspective in the proceedings. The Chaplain should, at the conclusion, particularly note spiritual resources and activities which are apt to enhance wholeness following the debriefings, similar to referrals made to mental health and physical resources and activities. Chaplains shall take the basic and advanced courses for CISM.

Peers: These are volunteers and should be drawn from similar professions and similar areas of responsibility. Selection criteria for peers are:

- (a) Emotionally mature
- (b) Good communication and interpersonal skills
- (c) Ability to transcend the scope of gender
- (d) Have at least two years training and participation in CISM
- (e) Recommended for peer duties by chaplains or team coordinators

CONTINGENCY PLAN

CISM teams should have a plan that includes these elements: a risk assessment identifying high-risk persons or groups, a survey of CISM resources within the program and a response plan outlining the activation process.

COORDINATION

CISM teams shall coordinate their interventions with other ongoing activities at the affected locations and for the affected personnel or individuals.

CISM SERVICES

Teams shall carry out procedures in accordance with policy and procedure.

PRE-INCIDENT PREPARATION TRAINING

Pre-incident training helps individuals prepare to cope with death, crisis and traumatic events. People forewarned about traumatic stress generally are able to manage it better and tend to recognize its signs earlier. It is useful for everyone facing exposure to a traumatic event and promotes optimal performance.

- Establish a certified intervention and referral resources for CISM within the geographic area.
- Coordinate establishing CISM teams.
- Ensure CISM personnel selected as peer support personnel are trained in CISM interventions.
- Maintain a roster of trained peer support personnel.
- Approve peer support personnel for interventions.
- Coordinate CISM pre-incident preparation training.

Ensure CISM confidentiality and effectiveness. No team member shall make any written notes during or about a CISM intervention. An after action report may be used by team members only to discuss at team meetings as to lessons learned about the intervention process. The after action report shall be very generic and shall not include names or any specifics about the intervention.

CRITICAL INCIDENT STRESS DEFUSING

This is a small group process ideally done within 8 hours after a critical incident. Post traumatic stress disorder (PTSD) frequently results from not talking about and being able to put into perspective a critical incident. Once PTSD develops, the impairment the long-term emotional response to the trauma causes is almost impossible to heal. Prevention is preferred. Any CISM team member can defuse. The process's objectives are:

- Rapid reduction in the intense reactions to a traumatic event
- “Normalizing” the experience so people can return to their routine as quickly as possible
- Re-establishing the group's social network so people do not isolate themselves from each other. In recognizing similarities to others, people often are more willing to help each other in troubled times.
- Assessing personnel to determine if a full debriefing is necessary

CRITICAL INCIDENT STRESS DEBRIEFING (CISD)

This is a group meeting or process using both intervention and education to mitigate or resolve the psychological distress associated with a critical incident. To maximize effectiveness, a debriefing should occur 24 to 72 hours after an event. CISD usually uses all team members: a mental health professional as leader or co-leader, chaplain, and peers. It is not therapy even though mental health professional(s) are part of the team.

A Debriefing:

- Is a group session led by a CISM Team of specially trained individuals
- Is not a critique or a performance evaluation
- Helps participants to focus on the event and share their thoughts and feelings
- Is confidential
- Is usually conducted within a 60-90 minute time frame

Personnel benefit from a Debriefing because it:

- Provides a supportive and caring atmosphere
- Helps participants to identify the signs/ symptoms of normal reactions
- Reduces feelings of isolation and inadequacy
- Contributes to the prevention of burn-out
- Provides reassurance and support to others
- Provides better coping skills for future incidents

Why offer a Debriefing?

The purpose of the debriefing is to take the active memories of the event and store them into long term memory. After a traumatic event our minds work to bring “closure” to the incident. Until closure is reached our minds continue to run a memory track of the event in hopes of making the incident make sense and be logical.

We continue to “turn over” the situation and review it until our minds feel satisfied that it “now makes sense.” A major consequence of a traumatic event is that the person feels that order and control in their life has been lost. The brain keeps turning over the sequence of events to regain order and control. In a debriefing a trained person helps the individuals understand the event, their lack of ability to control situations and then to store the incident into long term memory. Not all situations or persons need a debriefing, but for those persons who continue to not sleep, have anger issues emerge, or continue have difficulty in focusing attention a debriefing may prevent post traumatic stress.

OBJECTIVES

- To provide means for emotional expression by individuals involved in the event
- Accelerate recovery processes in people experiencing normal stress reactions to the critical incident
- To decrease distressing symptoms and prevent onset of PTSD
- To assimilate the traumatic experience of death and dying
- To regain/increase capacity for self-control
- To reduce the focus of the event in the daily lives of survivors
- To provide emotional support/enhance group cohesion
- To dispel myths and reduce self-blame

- To restore adaptive levels of trust
- To restore capacity for emotional response
- To alleviate disabling fears and anxieties caused by the trauma
- To provide structure and stability
- To prepare for physical and psychological symptoms that may follow
- To inform individuals about stress, stress reactions and survival methods
- To promote appropriate and realistic problem-solving
- To assess individual coping skills & make referrals if necessary
- To identify and access additional resources or support systems
- To arrange for effective follow-up
- To obtain closure
- To mitigate the impact on
 - Primary victims, those directly traumatized by the incident
 - Secondary victims, emergency services personnel who witnessed or managed the critical incident
 - Tertiary victims, dependent family members

ON-SCENE SUPPORT SERVICES

Services provided under “on-scene” conditions are brief, practical crisis intervention functions to limit the level of distress personnel encounter. On-scene support does not interfere with procedures.

These service providers usually are peers, with chaplains or mental health professionals called only as needed. The process objectives are:

- Stabilize the situation and protect from additional stress.
- Mobilize a wide range of resources to assist distressed persons.
- Normalize the experience and reduce the feelings of uniqueness and abnormality.
- Restore to function as quickly as possible.

DEMOBILIZATION

Demobilizations are generally used during a disaster or in a large-scale catastrophic critical incident. A primary stress prevention and intervention technique, it is applied immediately after personnel are released from the scene and before they return to normal duties.

Its two segments are, first, a 10 to 15 minute lecture on understanding and managing stress reactions and, second, a 20 minute rest and eating session. The process objectives are:

- Providing a transition from the traumatic event to normal routines.
- Reducing the intensity of immediate stress reactions.
- Assessing preliminary group needs for additional support services.

- Forewarning participants about potential reactions.
- Providing information about the incident and members' reactions.
- Providing practical information for managing stress and establishing linkages for additional support.
- Establishing positive expectations about outcome.

FOLLOW-UP SERVICES

If CISM provides initial services post-incident, follow-up services are **mandatory**. The chaplain is responsible for ensuring follow-up services are provided or accessible. Peers may be used if they have added training and experience in such services as individual crisis intervention; family debriefings; and/or referral to other mental health services.

EYE MOVEMENT DESENSITIZATION AND REPROCESSING

Eye Movement Desensitization and Reprocessing, or EMDR, is a powerful new psychotherapy technique which has been very successful in helping people who suffer from trauma, anxiety, panic, disturbing memories, post traumatic stress and many other emotional problems.

Until recently, these conditions were difficult and time-consuming to treat. EMDR is considered a breakthrough therapy because of its simplicity and the fact that it can bring quick and lasting relief for most types of emotional distress.

EMDR is the most effective and rapid method for treating PTSD (Post Traumatic Stress Disorder) as shown by extensive scientific research studies.

The EMDR therapy uses bilateral stimulation, right/left eye movement, or tactile stimulation, which repeatedly activates the opposite sides of the brain, releasing emotional experiences that are “trapped” in the nervous system. This assists the neurophysiological system, the basis of the mind/body connection, to free itself of blockages and reconnect itself.

As troubling images and feelings are processed by the brain via the eye-movement patterns of EMDR, resolution of the issues and a more peaceful state are achieved.

HOW DOES IT WORK?

The therapist works gently with the client and asks him/her to revisit the traumatic moment or incident, recalling feelings surrounding the experience, as well as any negative thoughts, feelings and memories. The therapist then holds her fingers about eighteen inches from the clients face and begins to move them back and forth like a windshield wiper.

The client tracks the movements as if watching ping pong. The more intensely the client focuses on the memory, the easier it becomes for the memory to come to life. As quick and vibrant

images arise during the therapy session, they are processed by the eye movements, resulting in painful feelings being exchanged for more peaceful, loving and resolved feelings.

WHAT PROBLEMS ARE HELPED BY EMDR?

The studies to date show a high degree of effectiveness with the following conditions:

- Loss of a loved one
- Injury of a loved one
- Car accident
- Fire
- Work accident
- Assault
- Robbery
- Rape
- Natural disaster
- Injury
- Illness
- Witness to violence
- Childhood abuse
- Victims of violent crimes
- Performance and test anxiety
- Trauma depression
- Anxiety or panic
- Phobias
- Fears
- Childhood trauma
- Physical abuse
- Sexual abuse
- Post traumatic stress
- Bad temper
- Overwhelming fears
- Panic attacks
- Low self-esteem
- Relationship problems
- Brooding or worrying
- Trouble sleeping

The EMDR technique is most effective when used in conjunction with other traditional methods of therapy in treating these and many other emotional disorders. EMDR therapy can help clients replace their anxiety and fear with positive images, emotions and thoughts.

WHAT SYMPTOMS ARE HELPED BY EMDR?

- High anxiety and lack of motivation
- Depression
- Memories of a traumatic experience
- Fear of being alone
- Unrealistic feelings of guilt and shame
- Fear of being alone
- Difficulty in trusting others
- Relationship problems

WHAT IS THE HISTORY OF EMDR?

Since the initial medical study in 1989 positive therapeutic results with EMDR have been reported with the following populations:

- People who have witnessed or been a victim of a disaster or traumatic event (rape, accidents, earth quakes, fires, murder, gang related violence)
- Clients suffering from PTSD (post traumatic stress disorder)
- Suffers of panic disorders and anxiety attacks
- Suffers of phobias
- Chemically dependent clients
- Persons exposed to excess loss (loss by death, divorce, house by fire)
- Crime victims and police officers who were once overcome with violent memories
- Accident or burn victims

Although a fairly new therapeutic technique, EMDR is meeting with much success all across the county. EMDR is a natural process. The client and the therapist become partners on a journey to help move traumatic and blocked energy. Together they work to transcend and free up the energy, so the client can return to their natural grounded state of being. The goal of this work is to help the client heal, so they can return to their life in peace.

HOW DO I KNOW IF EMDR IS RIGHT FOR ME?

There are a number of factors to consider when evaluating the appropriateness of EMDR therapy for a client's particular situation and history. During your initial consultation with a trained EMDR therapist, all the relevant factors will be discussed in full to help you both come to a decision to move forward with EMDR.

NOTES

Module 10

Hospice Manual

Quiz

Name: _____ Date: _____

Read each question carefully and place the correct answer in the space provided. Use additional paper if needed.

1. Prepare a written, in-depth self-care plan for yourself.

2. A small group process ideally done within 8 hours after a critical incident is called a _____.

3. A group meeting or process using both intervention and education to mitigate or resolve the psychological distress associated with a critical incident is called a _____.

4. _____ are generally used during a disaster or in a large-scale catastrophic critical incident.

5. Explain your understanding of how EMDR works.

COMPASSION FATIGUE - Self-Test

This self-test is not intended to provide medical advice or any diagnosis. Consult a physician or mental health professional if you think you might be suffering from Compassion Fatigue.

Consider each of the following characteristics about yourself and your current situation. Write in the number for the best response. Use one of the following answers.

1= Rarely/Never

2= At Times

3= Not Sure

4= Often

5= Very Often

- _____1. I force myself to avoid certain thoughts or feelings that remind me of a frightening experience.
- _____2. I find myself avoiding certain activities or situations because they remind me of a frightening experience.
- _____3. I have gaps in my memory about frightening events.
- _____4. I feel estranged from others.
- _____5. I have difficulty falling or staying asleep.
- _____6. I have outbursts of anger or irritability with little provocation.
- _____7. I startle easily.
- _____8. While working with a victim, I thought about violence against the person (or persons) who was victimized.
- _____9. I am a sensitive person.
- _____10. I have had flashbacks connected to my clients and families.
- _____11. I have had first-hand experience with traumatic events in my adult life.
- _____12. I have had first-hand experience with traumatic events in my childhood.
- _____13. I have thought that I need to “work-through” a traumatic experience in my life.
- _____14. I have thought that I need more close friends.
- _____15. I have thought that there is no one to talk with about highly stressful experiences.
- _____16. I have concluded that I work too hard for my own good.

Items about your clients and their families:

- _____17. I am frightened of things traumatized people and their family have said or done to me.
- _____18. I experience troubling dreams similar to a client of mine and their family.
- _____19. I have experienced intrusive thoughts of sessions with especially difficult clients and their families.
- _____20. I have suddenly and involuntarily recalled a frightening experience while working with a client or their family.
- _____21. I am preoccupied with more than one client and their family.
- _____22. I am losing sleep over a client and their family's traumatic experiences.
- _____23. I have thought that I might have been “infected” by the traumatic stress of my clients and their families.
- _____24. I remind myself to be less concerned about the well-being of my clients and their families.
- _____25. I have felt trapped by my work as a helper.
- _____26. I have felt a sense of hopelessness associated with working with clients and their families.
- _____27. I have felt “on edge” about various things and I attribute this to working with certain clients and their families.
- _____28. I have wished that I could avoid working with some clients and their families.
- _____29. I have been in danger working with some clients and their families.
- _____30. I have felt that some of my clients and their families dislike me personally.

Items about being a helper and your work environment:

- _____31. I have felt weak, tired, and rundown as a result of my work as a helper.
- _____32. I have felt depressed as a result of my work as a helper.
- _____33. I am unsuccessful at separating work from personal life.
- _____34. I feel little compassion toward most of my co-workers.
- _____35. I feel I am working more for the money than for personal fulfillment.
- _____36. I find it difficult separating my personal life from my work life.
- _____37. I have a sense of worthlessness/disillusionment/resentment associated with my work.

- _____ 38. I have thoughts that I am a “failure” as a helper.
- _____ 39. I have thoughts that I am not succeeding at achieving my life goals.
- _____ 40. I have to deal with bureaucratic, unimportant tasks in my work life.

SCORING INSTRUCTIONS

Make sure you have responded to ALL questions.

Next, circle the following 23 items: 1-8, 10-13, 17-26 and number 29.

Now ADD the numbers you wrote next to the items circled.

Note your risk of Compassion Fatigue

26 or LESS = Extremely LOW risk

27 to 30 = LOW risk

31 to 35 = Moderate risk

36 to 40 = HIGH risk

41 or more = Extremely HIGH risk

To determine your risk of Burnout, ADD the numbers you wrote next to the items NOT circled.

Note your risk of Burnout

19 or LESS = Extremely LOW risk

20 to 24 = LOW risk

25 to 29 = Moderate risk

30 to 42 = HIGH risk

43 or more = Extremely HIGH risk

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