

# Table of Contents

Section I:		
Welcome Letter		3
Joni Vallier, Operations Director		
Section II:	Hospice	
	Mission and Vision Statements	4
	Dr. Cicely Saunders, Founder, Hospice	5
	Hospice Definition	6
	Origins of Hospice	6
	Hospice Time Line	7
	Hospice of Southwest Iowa & Our Role	8
	Hospice Approach to Patient Care	9
	Hospice Medicare Benefits	10
	Members of the Hospice Team	11
	Admission Criteria	13
	Levels of Care	13
	Patient Rights	14
	Health Insurance Portability and Accountability Act (HIPAA)	17
Section III:	Volunteer training	
	Hospice Standards for Volunteers	19
	Job Description of Volunteer	20
	The First Visit	22
	Care and Comfort Measures	23
	Limits of Care to be Given by Volunteers	23
	Veteran specifics and special considerations	25
	Suicide	33
	Universal Precautions Against Infectious Diseases	35
	Emergency Situations	36
	Pain Relief in Hospice: A Holistic Approach	36
	Common Terminal Diagnoses	37
	Managing Personal Stress	38
	Relationship Boundaries.	39
Section IV:	Family Systems	
	Family's Response to Terminal Illness and Death	40
	Open and Closed Family Systems	40
	Levels of the Family	42
	Communication Techniques	42
	Spirituality	45

**Section V: Dying Process - Death**

Tasks of the Dying Patient	48
Emotional Reactions of Dying Patients and their Families	49
Loss	49
The Grief Process	50
Normal Grief Reactions	51
Manifestations of Grief	51
Basic Facts about Grief	52
Phases of Grief	52
Strategies to Help a Grieving Person	53

**Section VI: Bereavement Volunteer**

Ten Ways to Express your Sympathy	54
Tasks of Mourning	57
Children and Teen Grief	58
Adult Grief	59
Bereavement Services	60
Ideas for Caring Actions	60

# Hospice of Southwest Iowa

## **Welcome, New Veteran Volunteer!**

We are so glad you have made the decision to become a veteran volunteer for the Hospice of Southwest Iowa. As a new volunteer, you will be learning about what Hospice means, what services are provided, and how you can become an integral part of this program, while adding to the quality of persons served at end of life by Hospice of Southwest Iowa.

While some volunteers will decide their talents are best provided in indirect ways, such as office support, bereavement follow up, planning and assisting with activities such as bereavement gatherings and memorial services, others will want to be directly involved with patients and their caregivers. Both direct and non-direct volunteers are an important part of this program and the Hospice of Southwest Iowa would not be able to function without these volunteer services. In fact, Hospices are mandated by Medicare to 'employ' volunteers in order to add quality to patient's end of life care, assist caregivers to manage the care of the patient, and to assist with support services for the Hospice to function in an economical and efficient way.

This training manual will be a 'start' to build your knowledge of Hospice services. You will not be expected to know everything right away! Follow up training (in services) will be provided on a regular basis to assist you in broadening your understanding and comfort with Hospice information. You are encouraged to call the Hospice Volunteer Coordinator or Operations Director at any time if you have questions or concerns. And likewise, if you ever have any suggestions about enriching or improving the Hospice program, you are encouraged to share your suggestions.

Most of all, we want to thank you for your service to our county and for your continued support of fellow soldiers. Thank you for sharing your time, talent and treasure with Hospice of Southwest Iowa! You are making a difference by improving end of life care in Southwest Iowa with every service you offer.

Please sit back, get comfortable and enjoy your training! Ask questions, let us know your thoughts and feel free to share.

Best Wishes,

Joni Vallier, RN Operations Director Hospice of Southwest Iowa

# Hospice *of Southwest Iowa*

## **Mission Statement:**

**Cherishing life's journey through an extraordinary commitment to compassion, comfort, and holistic care.**

## **Vision Statement:**

**A community where all individuals and families share access to impeccable end of life care.**

# Hospice

*of Southwest Iowa*

**“You matter because you are you.  
You matter to the last moment  
of your life, and we will do all  
we can, not only to help you die  
peacefully, but  
to live until you die.”**

**Dr. Cicely Saunders**

# Hospice of Southwest Iowa

## **Hospice Definition**

(According to the National Hospice and Palliative Care Organization)

Hospice is a medically directed, nurse-coordinated program providing a continuum of home and inpatient care for the terminally ill patient and family.

An interdisciplinary care team, acting under the direction of the Hospice administration, provides palliative and supportive care for patients and families experiencing their own unique physical, emotional, social and spiritual needs.

Hospice care is available 24 hours a day, seven days a week, 365 days a year and is provided regardless of ability to pay.

## **The Origins of the Hospice Concept**

The term “Hospice” (from the same linguistic root as “hospital” and “hospitality”) stems back to medieval times when it was used to describe a place of shelter where weary or sick travelers could find shelter and temporary respite from their journeys.

Today, Hospice is a comprehensive model of care with services specially tailored for the terminally ill. Hospice was pioneered by Doctor Cicely Saunders, a British Physician and Social Worker. In the course of caring for a dying friend, it became apparent to Dr. Saunders that a more holistic system of care was needed. She recognized that terminally ill individuals had not only physical needs, but spiritual and psychological needs as well. When her friend died, he left her a large endowment for the purpose of creating the first Hospice.

In 1967, Dr. Cicely Saunders opened the first Hospice, St. Christopher’s Hospice in London, England. As the Hospice concept spread, Hospices in the British Isles and Canada initially concentrated on the inpatient setting. Hospice officially began in America in 1974 with the opening of Hospice, Inc. in New Haven, Connecticut. In 1983-1984, Medicare designed the Hospice Benefit and Conditions of Participation.

The basic principles for care espoused by Dr. Cicely Saunders were maintained, but the primary focus of care shifted to the home.

# Hospice Time Line

500 AD- 1450 AD	Religious orders establish services for the poor, sick and homeless.
1600 AD	Reformation- Hospitals establish their own identity; Monasteries were closed.
1900's	Sisters of Charity opened homes for dying patients in Dublin, Ireland.
1967	St. Christopher's Hospice is founded in England by Dr. Cicely Saunders.
1970's	Dr. Saunders comes to the United States to promote the Hospice vision at Yale University.
1974	Hospice is opened in New Haven, Connecticut through joint efforts of the Kaiser Foundation and the National Cancer Institute.
1977	National Hospice Organization (NHO) formed
1983	Medicare designed the Hospice benefit
1985	1,545 Hospice Providers in United States (NHPCO)
2007	4,700 Hospice Providers in United States (NHPCO)

# Hospice of Southwest Iowa

## Our Role

Hospice of Southwest Iowa, in collaboration with attending physicians, assists patients and families facing the final stages of life-threatening illness in the following ways:

- Assesses the current physical, emotional, social, and spiritual needs.
- Instructs and assists families in patient care and control of unwanted symptoms in collaboration with the patient's attending physician.
- Manages the patient's pain by using the least invasive means possible to preserve patient dignity and quality of life.
- Provides an interdisciplinary approach to care, maximizes consistency and continuity by developing a plan of care, and provides the attending physician with information concerning that care.
- Makes nursing, social work, nursing assistant, pastoral care, volunteer, and bereavement visits as necessary.
- Provides Advance Directives information that describes a patient's right to make decisions and to designate another person to make those decisions when the patient is no longer able to make them.
- Prepares and supports the patient and the family as they work through the dying process and feelings of grief. Provides 13 months bereavement after-care, and refers family members to grief support groups and private counseling when appropriate.

# Hospice of Southwest Iowa

## Hospice Approach to Patient Care

- Intervention, known as palliative care, focuses on the management of physical, spiritual and psychological symptoms.
- Active patient and family involvement in care plan.
- Pastoral care and bereavement services as an integral part of Hospice care.
- Interdisciplinary team care:
  - Medical director (physician)
  - Case manager/nurse
  - Social worker
  - Chaplain or spiritual care coordinator
  - Volunteers
  - Bereavement coordinator
  - Primary care physician
  - Others: Hospice aide, dietitian, pharmacist, physical and occupational therapists.
- Hospice services are available 24 hours a day/ 7 days a week on a scheduled and as needed basis.
- Inpatient services are available as well as home care with continuity of care across both settings.

# A Comparison of the Medicare Home Health Benefit and Hospice Benefit

Service	Medicare Home Health Benefit	Medicare Hospice Benefit
Nurse	Covered for skilled care if part time or intermittent	Covered for skilled and supportive care
Physician	Not covered under home care, but 80% of approved charge covered under part B	Attending physician 80% covered under part B; consulting physician 100% covered under Hospice Benefit, Hospice medical director consultations covered 100%
Social Work & Counseling Services	Covered for patient	Covered for patient & family (persons who play a significant role in the patient's life, including those who may or may not be legally related to patient)
Pastoral Counseling & Chaplain Services	Not covered	Covered
Home Care	Covered if part time or intermittent	Covered as specified in Hospice Plan of Care
Volunteers for Patient and Caregivers	Not Included	Included
Physical Therapy, Occupational Therapy, Speech & Language Pathology	Covered, with some limitations on occupational therapy	Covered as specified in Hospice Plan of Care
Dietitian	Covered with some limitations	Covered as specified in Hospice Plan of Care
Respiratory Therapy	Not covered for individual patients	Covered as specified in Hospice Plan of Care
Inpatient Care	Not covered	Covered as specified in Hospice Plan of Care
Respite Care	Not covered	Covered as specified in Hospice Plan of Care
Continuous Care	May be covered where need is finite & predictable	Covered as specified in Hospice Plan of Care, during period of medical crisis
Services to Nursing Facility Residents	Not covered	Covered if patient is Hospice eligible and facility and Hospice have written agreement

# Members of the Hospice Team

## Physician Services

Prior to a patient's admission into the Hospice program, the attending physician must provide the following information to the Hospice program:

- 1) Admitting diagnosis and prognosis
- 2) Current medical findings
- 3) Order for medications
- 4) Treatment for symptom management
- 5) Medical management of other conditions not related to the terminal illness
- 6) Designation of an alternative physician to contact regarding the patient's emergency care

The Hospice physician (medical director) provides the following:

- 1) Consults with the primary physician regarding pain and symptom management
- 2) Reviews of patient eligibility for Hospice services
- 3) Acts as a medical resource to the Hospice team
- 4) Acts as a liaison with other physicians in the community
- 5) Provides face to face visits as prescribed by Medicare

## Nursing Services

The case manager of a patient is a registered nurse who places special emphasis on:

- 1) Pain and symptom control
- 2) Physical, psychosocial, and environmental needs of the patient and family
- 3) Care in the home or other settings
- 4) Support and teaching for the patient and family
- 5) Documentation of problems and appropriate goals, interventions, and patient/family responses to care provided

## Hospice Aides

Hospice aides assist patients with their personal care tasks. With a focus on dignity and comfort, they assist patients with bathing and other personal care needs, assist the patient and caregiver with light household duties and other activities that foster a comfortable safe environment. All hospice aide services are based on case manager's initial and ongoing assessment and IDT recommendations of the patient's personal care needs.

## Social Work Services

Hospice Social Workers provide emotional support, counseling and guidance to the Hospice patients and families in coping with stresses related to the illness. The Social Worker assists the patient and family with community resources and education about Advance Directives or other end-of-life-issues.

## **Volunteer Services**

Well-trained Hospice volunteers work with professional staff to provide support for patients and families. Volunteers may provide listening, visits, companionship, respite care, and/or light errands for the patient or family, as well as pet therapy and music therapy.

Before working in a Hospice program, volunteers are required to complete an orientation program. Volunteers are not allowed to administer medications or provide hands-on care.

## **Pastoral Care**

Spiritual support and care is a vital part of the Hospice philosophy. Pastoral care may be provided by the Hospice chaplain and/or patient's pastor according to the requests of the patient, family or team. Pastoral care visits can be beneficial to both patient and family with anticipatory grief and loss, end-of-life goals, relationship closure, religious rituals and/or sacraments, and memorial service planning.

## **Bereavement Services**

Because grief continues with family members after their loved one has died, bereavement services are offered to all Hospice families. The Bereavement Specialist offers support to families during a 13 month period following a patient's death and coordinates the bereavement program. Services include grief classes, support groups and individual support as desired. Special gatherings similar to memorial services are held throughout the year for families and staff. Referrals to outside sources when necessary to assist with complicated grief.

## **Pharmacy Services**

The services of area pharmacies are available to Hospice patients. The Hospice team consults with the pharmacist regarding the provision of medications ordered by the physicians for palliation and pain management.

Several other services are available to Hospice patients when needed such as dietary, infusion, speech therapy, occupational therapy and physical therapy.

# Admission Criteria

Patients must meet certain admission criteria requirements to be eligible for Hospice services. Hospice services will be available to those meeting such requirements without regard to race, color, national origin, creed, age, sex, disease process, or ability to pay.

The following criteria must be met for admission into a Medicare certified Hospice program:

- Patient has a terminal illness with limited life expectancy of 6 months or less.
- Patient and family have knowledge of the terminal illness.
- Patient and family are informed of and accept the Hospice philosophy of care (Palliative approach to care, comfort over cure) and elect in writing to receive Hospice care.
- No extraordinary means to prolong life or hasten death are wished by the patients and families.
- A primary caregiver is designated to assume the responsibility of care. If the patient lives alone, an individual (or individuals) is designated to assume responsibility for providing care to the patient or making alternative living arrangements for the patient, in the event that the Hospice team determines that the patient cannot safely remain alone.
- Physician gives a written order for Hospice services with certification of limited life expectancy (6 months or less) providing the disease runs its normal course. The hospice Medical Director must also agree the patient meets criteria.
- Patient lives in designated area served by the Hospice.

## Levels of Care

**Routine Care** – is provided in a residential setting, usually a patient’s home or a long-term care facility. This level of care can also be given in an assisted living facility. The needs of the patient determine how often the patient will be seen.

**Inpatient Care** - is designed for short-term, acute needs, which are provided in a contracted inpatient unit, hospital or skilled nursing facility when a patient’s symptoms cannot be managed in the residential setting with the routine level of care.

**Continuous Care** – is provided in a residential setting when the patient is in crisis and symptoms cannot be managed with the routine level of care. This level of care is sometimes initiated to prevent transfer to an inpatient setting.

**Respite Care** – is provided as short-term relief to a patient’s primary caregivers by transferring the patient to a Hospice inpatient unit, hospital or skilled facility for up to five days.

# Hospice Patient / Family Rights

## Patients have the right to:

- Have a relationship with HSI staff that is based on honesty and ethical standards of conduct to have ethical issues addressed and to be informed of any financial benefit Hospice receives if Hospice refers patient to another organization, service, individual or other reciprocal relationship.
- Mutual respect and personal dignity for both the patient and caregiver. HSI staff is prohibited from accepting gifts or from borrowing from the patient or family.
- Receive considerate, respectful care in their place of residence at all times without regard to race, color, creed, gender, sexual orientation, age, national origin, ability to pay or type of health problems and/or their advance directives.
- Exercise their religious and spiritual beliefs.
- Be free from psychological, physical, sexual and verbal abuse, neglect and exploitation.
- Be treated with respect, consideration, individuality and personal dignity. To ensure privacy in their treatment and in care for their personal needs, HSI will notify patients, if, for reasons of safety, education or supervision, an additional individual needs to be present for the visit.
- Have their property, personal privacy and security treated with respect during skilled home care visits. Patients have a right to unlimited contact with visitors and others and to communicate privately with these persons.
- Have their communication needs met.
- Receive information about Hospice of Southwest Iowa's policies and procedures.
- Participate in planning their care. The patient may request an explanation in writing of any services proposed, frequency of visits, and source of payment for care including eligibility for third party payment and any charges for which patient will be liable. HSI will also provide patient with names, qualifications and responsibilities of the individuals providing their care upon request.
- Be advised, verbally or in writing, before their care is initiated, the extent to which payment for services may be expected from Medicare, Medicaid, or other insurance plans, including their approximate maximum dollar amount of payment which may be required from them.
- Be advised, verbally or in writing, of any funding changes no later than 30 days from the date the organization becomes aware of these changes.

- Know, in advance, of any changes in the services to be provided to them.
- Know, in advance, of any changes in their Plan of Care.
- Receive information in terms that the patient and caregivers can understand, in order for them to give informed consent for their care.
- Receive information about their diagnosis, the possible out-come of the disease, and treatment options.
- Receive information about alternatives to care and the risks involved.
- Choose whether or not to participate in research, investigational drug trials, or experimental treatments. The patient's access to care, treatment and services will not be affected if he/she refuses or discontinues participation in research. Patient may refuse part or all of care/services to the extent permitted by law.
- Review all their health records (unless their physician feels it may be contraindicated).
- Receive both an oral and written explanation regarding termination. If services are terminated for any reason other than discharge, patient will receive information regarding community resources.
- Receive both an oral and written explanation regarding denial if services are denied. Information regarding community resources will be communicated.
- Expect that their reports of pain will be believed. The patient will receive information about pain and pain relief measures. Patient will be cared for by a concerned staff committed to pain prevention and management. Effective pain management will be implemented according to the plan for care.
- Education about their role and their family's role in managing pain when appropriate, as well as potential limitations and side effects of pain treatments.
- Accept or refuse medical care, treatment and services and to be informed of health consequences of this action.
- Formulate Advance Directives (Living Will or Durable Power of Attorney) and have health care providers comply with their advance directives in accordance with state laws.
- Expect confidentiality of written, verbal and electronic information including their medical records, information about their health, social and financial circumstances or about what takes place in their home. The Notice of Privacy Practices for HSI describes patients' rights in detail.
- Refuse filming or recording or revoke consent for filming or recording or care, treatment and services for purposes other than identification, diagnosis and treatment.

- Access, request changes to and receive an accounting of disclosures regarding their own health information as permitted by law.
- Communicate with their care providers to maintain reasonable continuity and quality of care.
- Know that the HSI organization has personnel and resources for resolving ethical issues regarding their care.
- Voice grievances and suggest changes in their services or staff without fear of coercion, reprisal or discrimination. Patients have the right to expect no unreasonable interruption of care, treatment or services for voicing grievances.
- Choose their health care providers and communicate with those providers.
- Be referred to another organization, if they desire.
- Know that their compliments, concerns or complaints of the HSI services can be made by them or their family by calling 712-352-1389 (Council Bluffs) or 641-322-6283 (Corning) and speaking with the Hospice Operations Director. Concerns and complaints will be investigated and documented within two business days. Patients, their families, and staff have the right to know about the results of such complaints.
- Be informed of the 24-hour Hospice Hotline for complaints, questions and information at 712-323-5989.
- Know that the HSI organization will provide services to them only if HSI has the ability to do so safely and professionally at the level of intensity needed.
- Have their family involved in decision making concerning their care, treatment and services, when approved by them or their surrogate decision maker and when allowed by law.

# HIPAA Basics

The Health Insurance Portability and Accountability Act (HIPAA) were passed by Congress in 1996 to set a national standard for electronic transfers of health data. At the same time, Congress saw the need to address growing public concern about privacy and security of personal health data. The task of writing rules on privacy eventually fell to the U.S. Department of Health and Human Services (DHHS). After several modifications, DHHS issued the HIPAA Privacy Rule. The Privacy Rule went into effect on April 14, 2003, for most health care providers, health plans, and health care clearinghouses.

HIPAA covers any information about a patient's past, present or future mental or physical health including information about payment for their care. To be covered by HIPAA, information has to be kept by a covered entity – a health care provider, health care plan, or health care clearinghouse. This combined with some fact that identifies the patient (name, address, telephone number, and Social Security number), is called “protected health information” or PHI. PHI can be oral, handwritten, or entered into a computer. This means a conversation between a doctor and nurse about a patient's condition has the same general protections as information written on the patient's records.

There are criminal and civil penalties for:

- Failure to comply with the HIPAA requirements
- Knowingly or wrongfully disclosing or receiving health information
- Obtaining information under false pretenses
- Obtaining information with intent to:
  - Sell or transfer it
  - Use it for commercial advantage
  - Use it for personal gain
  - Use it for malicious harm

Your responsibilities and HIPAA

- Curb human nature in being curious and sharing information
- Are sensitive to issues
- Respect the patient's right to privacy
- Treat the patient's information the way you would want your information treated

It is our goal to maintain patient trust that their medical records are protected and their confidential information is kept private.

## Examples of Privacy Violations

Concerns about the lack of attention to information privacy in the health care industry are not merely theoretical. In the absence of a national legal framework of health privacy protections, consumers are increasingly vulnerable to the exposure of their personal health information. Disclosure of individually identifiable information can occur deliberately or accidentally and can occur within an organization or be the result of an external breach of security.

## Examples of recent privacy breaches include:

The 13-year-old daughter of a hospital employee took a list of patients' names and phone numbers from the hospital when visiting her mother at work. As a joke, she contacted patients and told them they were diagnosed with HIV. ("Hospital Clerk's Child Allegedly Told Patients That They Had AIDS," *The Washington Post*, March 1, 1995, p. A17)

A banker who also served on his county's health board cross-referenced customer accounts with patient information. He called due the mortgages of anyone suffering from cancer. (M. Lavelle, "Health Plan Debate Turning to Privacy: Some Call For Safeguards on Medical Disclosure. Is a Federal Law Necessary?" *The National Law Journal*, May 30, 1994, p. A1)

Renee McIntosh is suing a San Francisco law firm that represents her employer, Safeway. McIntosh claims that the firm shared information - including a psychiatric evaluation - about her workers' compensation claim with a co-worker. (K. Flaherty, "Litigation Privilege vs. Privacy Is Issue in Suit," *American Lawyer Media*, April 9, 1999, p. 2)

A psychiatrist from New Hampshire was fined \$1,000 for repeatedly looking at the medical records of an acquaintance without permission. Because there was no state law making it a crime to breach the confidentiality of medical records, the case was brought under a law against misusing a computer. ("Psychiatrist Convicted of Snooping in Records," *The Associated Press State & Local Wire*, May 5, 1999)

A jury in Waukesha, Wisconsin, found that an emergency medical technician (EMT) invaded the privacy of an overdose patient when she told the patient's co-worker about the overdose. The co-worker then told nurses at West Allis Memorial Hospital, where both she and the patient were nurses. The EMT claimed that she called the patient's co-worker out of concern for the patient. The jury, however, found that regardless of her intentions, the EMT had no right to disclose confidential and sensitive medical information, and directed the EMT and her employer to pay \$3,000 for the invasion of privacy. (L. Sink, "Jurors Decide Patient Privacy Was Invaded," *Milwaukee Journal Sentinel*, May 9, 2002)

No matter how or why a disclosure of personal information is made, the harm to the individual is the same. In the face of industry evolution, the potential benefits of our changing health care system, and the real risks and occurrences of harm, protection of privacy must be built into the routine operations of our health care system.



# Volunteer Training

## Hospice Standards for Volunteers

Hospice utilizes and values specially trained, caring volunteers that are capable of assisting the population served by the Hospice program.

Hospice must use volunteers to the extent specified in the Conditions of Participation (CoPs) 2008. Volunteers must be used in defined roles and under the supervision of a designated hospice employee.

### **Standards:**

**Training** – the hospice must maintain, document, and provide volunteer orientation and training that is consistent with hospice industry standards.

**Role** – volunteers must be used in day-to-day administrative and/or direct patient care roles.

**Recruiting and Retaining** – The hospice must document and demonstrate viable and ongoing efforts to recruit and retain volunteers.

**Cost-saving** – The hospice must document the cost savings achieved through the use of volunteers. Documentation must include the following:

- (1) the identification of each position that is occupied by a volunteer.
- (2) the work time spent by volunteers occupying those positions.
- (3) estimates of the dollar costs that the hospice would have incurred if paid employees occupied the positions identified above in (1) of this section for the amount of time specified in (2) of this section.

**Level of Activity** – Volunteers must provide day-to-day administrative and/or direct patient care services in an amount that, at a minimum, equals 5 percent of the total patient care hours of all paid hospice employees and contract staff. The hospice must maintain records on the use of volunteers for patient care and administrative services, including the type of services and time worked.

# Job Description of Veteran Volunteers

## Qualifications:

Veteran volunteers must be a Veteran. A Veteran is defined as a person who has served in a military force. Veteran volunteers must have a professional appearance, maintain own good health, respect patients' confidentiality, and be reliable, honest, dedicated and flexible. Veteran volunteers must be aware of special circumstances and situations of patients and caregivers and be compassionate and good listeners.

## Position Purpose:

This position contributes to the mission and vision of Hospice of Southwest Iowa (HSI) by serving as an advocate for patient, family and payer to achieve negotiated and positive outcomes, manage related costs, and ensure consumer inclusion and satisfaction with the outcome. Key program responsibilities include:

Visit with Veteran patients and families recommended and assigned by HSI Volunteer Coordinator. Provide the Veteran patient with companionship, interaction, comfort, and provide the caregiver(s) with emotional support.

Demonstrates the core values and mission of HSI and adopts the Agency mission, strategic direction and project goals.

## Application and Training Procedures:

Following an initial pre-screening, Veteran volunteers will complete a 16-hour training involving all disciplines on the Hospice team. This initial training will include viewing HIPAA regulations and pertinent information regarding Hospice of Southwest Iowa policies and procedures.

Hospice Administration, Volunteer Coordinator, and the Veteran Volunteer will make a mutual decision in determining the appropriateness in completion of training. The Volunteer Coordinator will summarize the initial interview and place information in the candidate's personnel file.

- Upon hire, the Veteran Volunteer will keep all commitments. The Veteran Volunteer will call the Volunteer Coordinator if unable to serve as a volunteer, if vacationing, and/or ill.
- An in-service training will be provided on a regular basis, usually monthly to all veteran volunteers.
- Length of commitment to Hospice of Southwest Iowa: one year from date of return of background checks. A renewal of this commitment can then be made yearly.

If the Veteran volunteer is negligent with patient, is not accountable for volunteer performance and volunteer assignment notes, and does not attend mandatory in-services, then the volunteer must be dismissed.

## Principle Accountabilities:

1. Participates in all safety, security, and infection control programs that are mandatory as well as those required and provided by the department.
2. Demonstrates work practices consistent with HSI and department-specific safety, security, and infection control policies.
3. Demonstrates and role models the HIS mission, vision, and commitments in daily behavior.
4. Values and embraces multicultural traditions and recognizes when there is a need for and procures translations/interpretations appropriately.
5. Complies with all internal and external regulations, Medicare Conditions of Participation and policies and procedures. Demonstrates understanding and practices of HIPAA regulations.
6. Provides ideas, comments and recommendations through established forums, team meetings, steering groups, and leadership communications and in any opportunity for open dialogue.
7. Maintains awareness of regulatory guidelines governing the Hospice industry to ensure compliance within the volunteer program.
8. Carry out other assignments as may be appropriate.

## Visit report

Veteran volunteers must complete the Visit Report Form each time they visit the Veteran patient. The visit report is **essential** to team continuity.

The Veteran volunteer will deliver or mail in the Visit Report to the Volunteer Coordinator within an agreed upon time. Stamped and addressed envelopes will be provided.

The Veteran volunteer will provide service to Veteran patient(s) per identified need. To provide continuity of care, the Veteran Volunteer will keep scheduled day/time. If unable to visit, the volunteer will:

- a. Call the Volunteer Coordinator, and
- b. Call the patient/family

# The First Visit

The first visit is sometimes difficult. “Will they like me?” “Will I be able to help?” “What will I do?” These questions are natural. Just remember at these times that you have been selected to be a Hospice Team Member because people have confidence in you. Just “plunge in”. Bring to the situation an attitude of openness and receptivity. The family and the patient will let you know what they need and you will let them know what you can offer. Here are some guidelines that may be helpful:

## **Genuineness**

Be yourself. Aside from modifications in behavior to assure the comfort of the patient, such as less talking, more listening and conscious attentiveness, the volunteer should relate with the same personality he/she displays in any other situation. Relate to the patient, not to the illness.

## **Communication with the volunteer coordinator is essential.**

You are a team and can be of great assistance to one another and to the patient and family by maintaining regular contact and keeping one another current with what is going on. Do not be afraid to take the initiative in establishing a relationship. Exchange schedules and appropriate telephone numbers. Clarify mutual expectations of one another from the start.

## **Dependability**

The lives of Hospice families and patients are subject to much unpredictability. It is essential to know that they can count on you. Never offer more than you know you can deliver.

## **Listening**

Always remember that your function as a volunteer is first to meet the needs of your patient and family, rather than your own. It may mean listening to the same stories repeatedly. It may mean listening to outbursts of anger or frustration. You may even be the target of the negative feelings. Do not take it personally. People under severe stress often misplace their emotions.

## **Confidentiality**

References to the patient/family should be confined to contacts with the Hospice Team, either individually or at meetings.

## **Wonderful Moments You Will Experience:**

We all need a time-out, and caring for a loved one can be exhausting. The special time you are giving the patients and families is valuable. Brightening the day of a person who feels down can make YOUR day. Bring some sunshine by telling a good joke; if the patient is able to walk – take a stroll outside. Converse about their family, look at photographs, and bring them some sunshine.

# Care and Comfort Measures

Hospice has policies for hands-on care provided by volunteers. Hospice of Southwest Iowa believes that touch can be an important part of the relationship with the patient/volunteer and that it is encouraged. The volunteer should determine if the patient would enjoy any comfort touch. "Comfort Touch" training is available through HSI.

Non-skilled care and comfort measures, such as feeding, assisting with wheelchairs, sit-stand transfers, walking and safety, must be discussed with the Hospice volunteer coordinator or nurse before performing.

Some responsibilities as a Hospice volunteer could include the following:

- Personal care and comfort measures.
- Washing face and hands.
- Apply soothing lotion to hands and feet.
- Filing and painting finger and toenails.
- Read, play music, or play cards/board games.
- Comb/brush hair, shave with electric shaver only.
- Light errands.
- Volunteers may reposition the patient using pillows and blankets for support.
- Facilitating life review/reminiscing (assist in developing written/recorded stories).
- Following instructions from the case manager and/or caregivers, a volunteer may make and give a snack or refreshment with precautionary measures.

## Limits of Care to Be Given By Volunteers

In situations where the volunteer provides respite to the family, the volunteer may follow procedures that have been set up by the family as a routine. However, this **does not** include any kind of physical nursing care.

Volunteers **may** assist the patient with:

- filing nails with an emery board.
- giving routine prosthesis help, e.g. assisting the patient with what he/she is able to do himself/herself - braces, canes and crutches.
- the patient's normal routine method of using a bed pan or other excretory appliances.
- using a wheelchair after a transfer by Hospice or facility staff with that specific patient.
- routine and customary comfort procedures.

Care that requires the use of considerable physical exertion **should not** be done. If the volunteer is requested to aid with such tasks (e.g. lifting patient, moving bed or furniture) the volunteer has the responsibility not to assist with the task, but to help the family locate the appropriate household help.

# “WHEN IN DOUBT, DON’T.”

## Volunteers **may not**:

- initiate the dispensing of any medications.
- cut nails or use any sharp objects in personal care.
- shampoo any patient, dye or stain hair, unless they are professionally trained to do so.
- help with ostomies, (surgical openings with drainage to outside of body).
- help with douches, enemas or any suctioning of the patient.
- dress wounds.
- initiate the use of heating pads, hot water bottles or cold packs.
- introduce any instrument, swab or object into any orifice.
- may not initiate care which requires physical exertion.

# Veterans and End-of-Life

*Adapted from material shared by HCI Care Services, Deborah Grassman, and the NHPCO*

Why is it important to have Veterans care for Veterans at the end-of-life:

- Military training and the culture of stoicism can often prevent Veterans from sharing difficult experiences.
- When one Veteran talks to another, stoicism and secrecy dissolve.
- Veterans share a common language and code of conduct.
- Sharing supports life review and healing!

Veterans and their loved ones have unique needs at the end-of-life. These needs are influenced by:

- Combat or non-combat experience
- Age
- Which war they served in
- If they were POWs
- If they have PTSD
- The branch of service and their rank
- Whether they were enlisted or drafted

\*The biggest influence for a Veteran at the end-of-life may be whether or not they served in combat. Additionally, the age at which the Veteran entered the military and the war era in which they served has a large affect on their perspective after the war.

## War Eras

### **WWII: Heroes**

WWII was a glamorized war. There was no television footage of this war and many Veterans lied about their age to be a part of this war. When Veterans returned home from WWII, they were welcomed with parades and open arms. They were called heroes.

### **Cold War/Korea: Ignored**

The Korean war is also known as the forgotten war. In fact, most would not even call this a war but rather refer to it as a “conflict”. The sacrifices made by our Veterans during the Cold War and Korean war have been minimized, if not totally forgotten.

### **Vietnam: Shamed**

Vietnam was a very controversial and political war. The nation was divided. Vietnam was also a very publicized war, the first in which television coverage was rampant. Guerilla warfare was first introduced during the Vietnam War and Veterans often could not identify the enemy. Veterans had to face extremely difficult experiences and make life altering decisions at the drop of a dime. Veterans have shared experiences of going out to retrieve bodies of American soldiers, only to find that the bodies have been “booby trapped” and explode when touched.

## **Gulf War, Operation Enduring Freedom, Operation Iraqi Freedom**

Hospices are now seeing an increase of patients' who have served in these wars. It is expected that Post-Traumatic Stress Disorder will be high amongst these soldiers, as well as other psychosocial issues not yet identified.

The war era in which a Veteran served and the way the Veteran views his/her military experience may impact their outlook on life, as well as death. Many Vietnam Veterans may believe the war was "lost" or all their efforts were for nothing, whereas World War II Veterans feel like heroes. There is a very different impact if a Veteran feels like a hero than if their suffering has no meaning.

It is also crucial to remember that women are Veterans too!

Many Veterans entered the military at a very young age. Young people are very impressionable, which makes age such an important factor of a Veteran's military experience. Having fought in combat (especially if that combat included having to kill another person) also largely impacts Veterans' perspective. For women, sexual assault may be another factor greatly affecting perspectives and coping.

(Grassman, Deborah. (2012, February). Care of Veterans at End of Life: War and Peace. Presented at Hospice of Central Iowa Institute, Des Moines, Iowa.)

# **POST-TRAUMATIC STRESS DISORDER (PTSD)**

Post-Traumatic Stress Disorder (PTSD) is an anxiety disorder that can develop after exposure to one or more terrifying events that threatened or caused grave physical harm (to self or other).

This is a specific psychiatric disorder in which a cluster of symptoms occurs beyond one month after someone experiences a traumatic event.

Trauma: an experience that is emotionally, physically and/or spiritually painful, distressful or shocking and which may result in lasting mental and physical effects.

Trauma reactions are NORMAL reactions to abnormal circumstances or events such as those in war. Trauma reactions are NOT indicative of moral weakness or sin.

PTSD is a mental, emotional, social, spiritual, moral, familial, and intergenerational injury.

Diagnostic Criteria of PTSD, as described in the DSM-IV:

- Exposure to a traumatic event experienced with fear, horror, or helplessness
- **Trauma is persistently re-experienced (1 or more):**
  - Recollections
  - Dreams
  - Acting as if trauma is recurring
  - Distress at cues that symbolize the trauma

- **Avoidance of associated trauma (3 or more)**
  - Avoidance of thoughts, feelings, conversations r/t trauma
  - Avoidance of activities, places, or people that arouse recollection
  - Inability to recall some aspects of the trauma
  - Lack of interest in significant activities
  - Feelings of detachment/estrangement from others (emotional amnesia/numbing)
  - Restricted range of affect
  - Sense of a foreshortened future
- **Persistent symptoms of Increased arousal (2 or more):**
  - Difficult sleep patterns (nightmares)
  - Irritability or outbursts of anger
  - Difficulty concentrating
  - Hyper vigilance (example: calling over and over or asking “where are you? Are you safe?)
  - Exaggerated startle response

Several stress factors may increase a Veteran’s PTSD risk, which may include:

- Severity
- Duration
- Proximity (Role in war) \*Marines and Army have higher rates of PTSD
- Some resources say that the single most influential risk is having killed another person. This greatly complicates end-of-life care.
- Traumatic Brain Injury (a physical injury to the brain).

When working with families of a Veteran suffering from PTSD, it is critical to understand that “PTSD is a mental, emotional, social, spiritual, moral, familial, and intergenerational injury. Healing requires interventions that address all dimensions of suffering. PTSD does not only affect the Veteran, but it affects the entire family. Often times, Veteran’s suffering from PTSD also suffer from higher rates of divorce and estranged family relationships.

Behavioral and emotional reactions, common coping mechanisms, to trauma may include:

- Substance abuse
- Self-destructive and impulsive behaviors
- Uncontrollable reactive thoughts
- Inability to make healthy lifestyle choices
- Dissociate symptoms (splitting off parts of self)
- Discarding previously sustained beliefs
- Compulsive behavior patterns
- Depression, spontaneous crying, despair and hopelessness
- Anxiety, panic attacks and general fearfulness
- Compulsive and obsessive behaviors
- Feeling out of control
- Irritability, anger, and resentment
- Withdrawal from normal routine and relationships
- Emotional numbness

(Klink, A., (2012, March) The Wounds of the Past: Post-Traumatic Stress and Aging. Amedisys Hospice, Durham North Carolina)

# Combat Response Trajectories

Deborah Grassman theorizes that assimilation of combat experiences can be viewed as three trajectories. Each Veteran will process their experiences of combat in a unique manner. For some, the experience will greatly impact the rest of their life and for others there will be little notable change. Below are the three trajectory responses in her theory:

## **Trajectory 1: Combat Trauma Successfully Integrated**

The Veteran has accepted his/her military/combat experience. The Veteran's day-to-day life is not negatively impacted by the experience. You may hear statements such as "I've faced death before in the war. I'm not afraid of death any more" or "I must have been spared for a purpose. If I didn't do that, it means my buddies died in vain".

Some Veterans may even experience a positive, life changing impact from combat experience. This is defined as a Post Traumatic Growth Experience. Veterans' lives may be improved by developing new methods of:

- Relating to others
- Open to new possibilities
- Personal strength
- Spiritual changes
- Appreciation of life

## **Trajectory 2: Combat Trauma APPARENTLY Integrated**

This trajectory is also known as "subclinical PTSD". In this trajectory we may witness delayed-onset PTSD, in which as the patient approaches the end-of-life, signs/symptoms of PTSD become apparent, where prior, the Veteran believed he/she had dealt with their military experience. As we age, our outward landscape begins to weaken and our inward landscapes get stronger; therefore, the walls Veterans' have built to appear as though "everything is fine" began to fall down and the anger and fear began to emerge.

The statement "I'm fine" may be translated into "I'm Freaked out, Insecure, Neurotic, and Empty".

Indicators a Veteran may have Apparent Integration of Trauma include:

- Acting out behaviors
- Workaholic or other addictive behaviors
- "White Knuckle Syndrome": Veteran appears hollow or aloof

## **Trajectory 3: Combat Trauma NOT Integrated**

This trajectory is also known as "PTSD". The Veteran's day-to-day life is greatly impacted by his/her war experience. You may hear statements such as "Most of my brothers remained in Vietnam", "I've been fighting that war every day since I returned", and "90% of me died in that war". Again, it is important to remember that PTSD affects the ENTIRE family. You may hear family make statements such as "I didn't know the person who came back" or "We've been fighting that war every day since".

PTSD increases the likelihood a Veteran will have a lack of trust and/or suspicion, and an increased anxiety and agitation. Alcohol and drug use are also common coping mechanisms for these adverse feelings. Veterans suffering from PTSD are also more likely to have unfinished business, which in return will decrease the chances of a peaceful death, if not addressed. "War can rob men of their hopes and dreams of the future" (Deborah Grassman, 2012).

The three combat response trajectories are one way in which to view a Veteran's experience, although these are not utilized within the VA for diagnosing, or treating PTSD. Additional information regarding PTSD treatment and research can be found at <http://www.ptsd.va.gov/public/index.asp>

Below is a quote from a Vietnam Veteran, Edward M.:

**"I looked in the eyes of the dead man,  
And I saw peace.  
I looked into the eyes of the living,  
And I saw fear".**

# Healing

Deborah Grassman also theorizes that in order to heal, Veterans need forgiveness. He/she may have much to be forgiven for. A Veteran may need to forgive:

- Self (for killing)
- Self (for not killing, not dying, friendly fire)
- ENEMY
- Government (using/betraying them in Vietnam)
- The world (for being like it is)
- God (for allowing the world to be like it is)

Healing is a process that takes time, effort, and sometimes requires professional assistance. For some veterans', "forgiveness" is not enough.

(Grassman, Deborah. (2012, February). Care of Veterans at End of Life: War and Peace. Presented at Hospice of Central Iowa Institute, Des Moines, Iowa.)

Veterans' with PTSD actually develop an uncontrollable learned fear response. A Veteran may not feel he/she needs forgiveness, but memories of the atrocities will continue to haunt them. Additionally, Veterans may have significant spiritual suffering, which may include fear of retribution or retaliation that may await them in another life. A Veteran could achieve peace and forgiveness in some areas, but still be haunted in others (Schauer, Caroline, 2012).

## Why Veteran Volunteers are Important

Military training and the culture of stoicism can often prevent Veterans from sharing difficult experiences; however, when one Veteran talks to another, stoicism and secrecy dissolve. Veterans share a common language and code of conduct. Sharing supports life review and healing.

(Wade, T. (2011) Veterans Needs at the End-of-Life. IHPCA Fall Conference, Ames, Iowa.)

## What can we do? Interventions

Keep in mind that hospice is more than symptom control and pain management. The goal of hospice is to heal. Veteran volunteers are in the unique position of sharing a deep understanding with Veteran patients. This unique understanding makes the possibility of a deep emotional bond possible. Veteran volunteers can provide camaraderie and walk-beside another Veteran through his/her journey at the end of life.

In trajectory #1, no special intervention is necessary, other than what would be done for all hospice patients.

In trajectory # 2 and #3, it is vital for Veteran volunteers to allow the patient the opportunity to share their experiences, feelings, and thoughts. However, it is also important to NEVER push a Veteran into sharing anything experience if he/she is not ready. In trajectory #2, it is important to be aware of the behaviors and symptoms of PTSD in order to assist the hospice team to identify delayed onset PTSD.

In order to gain a better understanding of the Veteran's emotional pain, we may ask him/her to describe their emotional pain on a scale of 0 to 10:

**0=Serenity/10=Turmoil**

Once the Veteran has identified the number, have him/her describe what that number means from in his/her perspective. Furthermore, ask the Veteran what an acceptable number is and how that would look. It is always important to understand a Veteran's pain in his/her eyes. We must never assume we understand or know what a veteran is going through or feeling.

When a Veteran is sharing difficult memories/stories, the volunteer should allow him/her to share without adding statements such as "you did your best", "there was nothing else you could do". By doing so, we are playing down or minimizing the Veteran's pain. We must be "understanding and accepting of their pain, anger, shame, fear, and helplessness". Don't dismiss it with platitudes. Silence is often golden and our best approach to active listening. **Acknowledge their pain!**

**What we can do:**

- **Remember their behaviors are related to trauma (as described on page 27-28)**
- **Offer statements such as, "Some Veterans tell me they experienced some horrific things in war. Did anything like that happen with you?"**
- **After a question about war, sit quietly**
- **Don't touch unexpectedly. Call their name first**
- **Realize that noxious stimuli can re-stimulate trauma**
- **Assess for environmental triggers**
- **Offer camaraderie**
- **Keep the focus on the Veteran not you**
- **Remember the Veteran's experience may be different than yours**
- **Open the door, but never push**

**"If Vietnam or Korean Vets speak about how Americans treated them, apologize. If Vietnam Vets speak about never being welcomed home, welcome him."** (Deborah Grassman, 2012)

**When volunteering with ANY Veteran:**

- **Make the environment emotionally safe.**
- **Affirm the *feeling* aspect of their conversation.**
- **Remember that stoicism might interfere with acknowledging physical, emotional or spiritual pain.**
- **Recognize female Veterans:**
  - **Military nurses saw trauma/mutilation**
  - **Thank older female Veterans for paving the way**

- Look for PTSD in women
- May have been sexually assaulted in military

If you are seeing increased signs/symptoms of PTSD, notify hospice staff. Some medications may exacerbate the symptoms of PTSD and the case manager will need to address this immediately. Do not assume behaviors are PTSD related.

**Important Things to Remember:**

- Non-combat Veterans may have served on dangerous assignments.
- Stateside Veterans may have been facing dangerous deployments, but were never sent
- Combat Veterans may have served in “safe” areas
- Veterans in “safe” areas may have had to witness horrific traumas as they were transported and cared for off the battlefield
- Avoid making assumptions.
- Not all people who have suffered trauma will experience PTSD.

(Grassman, Deborah. (2012, February). Care of Veterans at End of Life: War and Peace. Presented at Hospice of Central Iowa Institute, Des Moines, Iowa.)

# Suicide

Veterans are at a higher risk of suicide. *Suicide is the intentional taking of one's own life.* Suicide is also something you can help a patient avoid. Hospice nurses and social worker are trained to assess all patients' suicide risk; however, it is important for volunteers to be familiar with the risk of suicide, as Veterans will often share more with a Veteran volunteer than he/she may with other hospice professionals. This subject can be controversial with several states allowing assisted suicide at the end of life. Veterans may see suicide as their way to maintain control at the end of life, but the role of hospice professionals is to address emotional, spiritual, and physical suffering and explore the option of living life as fully as possible.

## Who commits suicide?

- Women attempt suicide more than men
- More men than women commit suicide
- More common with age, but teenage rate is growing
- Suicide rates vary by race with Caucasians attempting more than African Americans

## Facts and Myths:

- MYTH: People who talk about suicide don't commit it.
- FACT: 80% of completed suicides had given definite indications of their intention
- MYTH: Talking about suicide will give someone an idea to do it.
- FACT: Suicidal people already have the idea. Talking about it may invite them to ask for help.
- MYTH: All suicidal people are fully intent on dying. Nothing can be done about it.
- FACT: 95% are undecided about it. They call for help before or after the attempt.
- MYTH: Suicide is an impulsive act.
- FACT: Most suicides are carefully planned and thought about for weeks.
- MYTH: A person who attempts suicide will not try again.
- FACT: Most people who attempt suicide have attempted to so before.
- MYTH: Improvement follows a suicidal crisis.
- FACT: Most suicides occur within 90 days after the beginning of "improvement". The decision to solve one's problems through suicide might offer the patient relief.

## Suicide Warning Signs:

***Nearly 80% of those who attempt or commit suicide give some CLUES to their intentions.***

Most warnings signs will present in either verbal or behavioral warnings.

Some verbal warnings that a patient may be contemplating suicide include statements such as:

- "I'm going to kill myself!"
- "I'd be better off dead."
- "I just can't go on any longer."
- "You won't be seeing me around anymore."
- "I'm getting out, no matter what."
- "I'm going home real soon."

Some behavioral warnings that a patient may be contemplating suicide include:

- Organizing business and personal matters
- Giving away possessions
- Composing a suicide note
- Buying a gun
- Planning one's own funeral
- Obsession with death
- A sudden lift in spirits

**Signs a patient may be depressed:**

- Withdrawal
- Overwhelming sadness
- Lack of energy
- Irritability
- Emotional flatness or emptiness
- Changes in behavior and attitude
- Different feelings and perceptions
- Physical complaints

**Patient's at the greatest risk of suicide may have:**

- Made a previous suicide attempt
- A family history of suicide
- Lost a friend through suicide
- Been involved with drugs or alcohol
- A history of alcoholism in the family

**What to do:**

**You need to :**

- Take threats seriously
- Answer cries for help
- Contact the volunteer coordinator or other hospice on-call staff immediately.

**What NOT to do:**

**Make sure you do NOT:**

- Leave the person alone
- Assume the person is "not the type"
- Keep it a secret
- Act shocked
- Argue or reason
- Analyze
- Shock or challenge

(Wade, T. (2011) Veterans Needs at the End-of-Life. IHPCA Fall Conference, Ames, Iowa.)

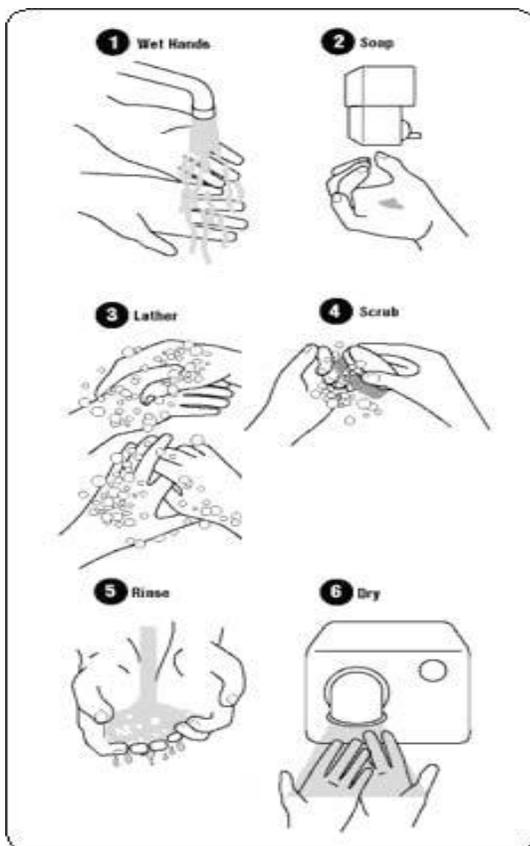
# Universal Precautions against Infectious Diseases

As you begin interacting with patients it is time to establish common sense habits to protect yourself and your patients from the spread of infectious agents. The commonly used term for the methods used is Universal Precautions - universal in that one uses these precautions with all patients, not just those with known or suspected infectious diseases. The agents associated with many infectious diseases are transmitted by superficial physical contact; others require intimate contact with blood or other body substances.

Infectious diseases are caused by viruses, bacteria, parasites, and fungi. These organisms can be spread from person to person through:

- blood and other body secretions
- droplets breathed/sneezed/coughed out from the nose/mouth
- skin-to-skin contact

Universal precautions help protect patients and their family, friends, and health care providers from infection.



Hand washing is performed frequently to protect both patients and health care workers. Hands are washed before touching patients, performing invasive procedures, and eating; hands are also washed after glove use, working with body substances, and using the toilet. Skin is a natural barrier to infectious agents, and products that protect and promote skin integrity can be used.

For effective hand washing, follow these steps: remove any rings or other jewelry,

- use hot water and wet your hands thoroughly,
- use soap (1-3 ml) (approx. 1 teaspoon) and lather very well,
- scrub your hands, between your fingers, wrists, and forearms with soap for 10 seconds,
- scrub under your nails,
- rinse thoroughly,
- turn off the taps/faucets with a paper towel,
- dry your hands with a single use towel or hot air dryer,
- protect your hands from touching dirty surfaces as you leave the bathroom.

## Other Universal Precautions

Gloves are worn for anticipated contact with all body substances that are exchanged between patients and sometimes between contacts with different sites on the same patient.

**Hospice of Southwest Iowa will provide you with a bag of supplies to take on each visit. Consult with the Volunteer Coordinator about other universal precautions.**

# Emergency Situations

Be familiar with safety regulations in case of fire or natural disasters and know the location of a fire extinguisher and exits from patient's home. In case of a tornado move the patient and/or the bed if he/she is bedfast away from windows, and cover patient with a blanket. Do not call 911 if a patient's medical condition deteriorates. Call the HSI office at 712-352-1389 in Council Bluffs or 641-322-6283 in Corning and ask for the nurse on call that will assist the volunteer. The Hospice number is prominently displayed in the patient's home, and the Hospice phone is answered 24 hours a day.

## Pain Relief in Hospice: A Holistic Approach

Pain is determined by both physiological and psychosocial factors and both must be addressed for an effective pain management program. Pain is a subjective experience; it is what the patient says it is, not what others believe it should be. Medication is not the only method of pain control.

Non-pharmacological methods of pain control can play an important role in helping to achieve adequate pain management.

The following are methods of pain control that may help the patient cope better:

- Pay attention to spiritual and emotional concerns of the patient. Spiritual distress is universal as the disease progresses and death approaches. Anger and fear are common emotions. These emotions are likely to be even more troubling if PTSD or late-onset PTSD is present.
- Provide companionship through a therapeutic relationship.
- Help the patient feel more relaxed and better able to cope. The following are some suggestions:
  - Ask the patient what helps them to relax
  - Facilitate activities that are accessible at bedside.
  - Encourage deep breathing, distraction, imagination.
  - Assist in facilitating life review.
  - Use simple relaxation techniques such as head rolls, finding a patient's favorite daydream and talking him/her through sensory cues.

*Adapted from: Hospice Operations Manual by Linda Kilburn, 1989, pp. 167-171. National Hospice Organization: Arlington, Virginia. Reprinted with the permission of NHO, all rights reserved.*

# Common Hospice Diagnoses

## Understanding Common Terminal Diagnosis

### Cancer

- The most common forms
- Cancer treatment and the side effects
- The role of palliative care and symptom management
- Non-cancer diagnosis:

Debility (multi-system failure)

AIDS

End Stage Heart Disease

End-Stage Lung Disease

End-Stage Renal Disease

Failure to Thrive

Neurological Diseases: e.g. Parkinson's disease, ALS, and Alzheimer's disease

# Common Physical Symptoms in Hospice Patients

Pain

Nausea and Vomiting

Anxiety or Restlessness

Shortness of Breath

Loss of Appetite

Constipation

# Secondary Losses That Accompany Terminal Illness

- Loss of autonomy
- Loss of bodily functions
- Loss of pleasure
- Loss of social contacts
- Loss of mobility
- Loss of environment and possessions
- Loss of experience
- Loss of ability to complete plans and projects
- Loss of various types of psychological, physical, and cognitive abilities
- Loss of hopes, dreams, wishes, fantasies, unfulfilled expectations, feelings, and needs
- Loss of predictability
- Loss of productivity
- Loss of identity
- Loss of self-esteem
- Loss of consistency
- Loss of control
- Loss of future existence
- Loss of meaning

# Managing Personal Stress

Working with hospice patients and families can be very stressful, especially when the situations presented are close to our hearts or we ourselves have experienced similar circumstances. Stress factors often associated with working with Hospice patients and families are:

- Physical: (weight loss/gain, frequent headaches, GI disturbances, insomnia, muscle tension, increased smoking/drinking, accidents)
- Anxiety: (anger, irritability, frustration, feeling stretched, overwhelmed, judgment errors, lability of mood, depression, excessive dedication, looking too busy)
- Interpersonal: (family resents long hours, power struggle, critical of family, distancing from family/long time friends, depersonalization of patients, intellectualization)
- Non-acceptance: (helplessness, inadequacy, insecurity, depression, guilt, no way to cope with mistakes, bad outcomes, losses at home, losses at work, death, loss of meaning or purpose).
- Hospice Veteran Volunteers may also experience their own military service memories while visiting patients who are Veterans. It is important that the volunteer be able to recognize and address their own feelings, emotions, and potential signs of Post Traumatic Stress Disorder.

## Coping Techniques to Use/Self Care

- Activities
  - Exercise regularly
  - Involve yourself in non-work activities
  - Become engaged in hobbies and outside interests
- Time Alone
  - Take time to step back
  - Analyze your situation to gain perspective
  - Learn to be in touch with your spiritual inner self
- Outlets for Emotional Expression
  - Talk with your family and friends
  - Express yourself in creative, imaginative ways
  - Listen to music, watch movies, attend plays, and read novels
- Rituals
  - Engage in rituals that bring people together
  - Create and seek out opportunities for support
  - Acknowledge your common and unique experiences
- Personal Philosophy
  - Be aware of your personal limits and boundaries
  - Be aware of your attitudes, assumptions, values and beliefs
  - Contemplate and seek out the discovery of meaning in your life
- Self-Awareness
  - Be aware of your own losses
  - Have an awareness of how your military training influences your thoughts and emotions

# RELATIONSHIP BOUNDARIES

## TIPS FOR SETTING BOUNDARIES

- When you identify your need to set a limit with someone, do it clearly—preferably without anger and in as few words as possible.
- You can't simultaneously set a boundary and take care of another person's feelings.
- You will probably feel ashamed and afraid when you set boundaries for the first time. Do it anyway. Do not be afraid!
- Anger, rage, complaining and whining are clues to boundaries you need to set.
- You will be tested when you set boundaries.
- Be prepared to follow through by acting in congruence with the boundaries you set.
- Some people are happy to respect your boundaries.
- You will set boundaries when you are ready and not a minute sooner.
- A support system can be helpful as you strive to establish and enforce boundaries.
- There is a pleasant side to boundary setting.

## SIGNS OF UNHEALTHY BOUNDARIES

- Trusting no one/everyone (black/white, either/or thinking).
- Relating on an intimate level on first meeting.
- Falling in love/infatuation with people who reach out.
- Being overwhelmed and preoccupied with someone.
- Acting on first sexual impulse.
- Going against personal values to please others/ inability to say no.
- Not noticing when someone else uses inappropriate boundaries.
- Not noticing when someone invades/violates your boundaries.
- Not returning personal items within agreed-upon time.
- Allowing others to take advantage of/take as much as they can from you.
- Letting others describe your reality and define you.
- Trying to define the reality of others-giving unsolicited advice, opinions, interrupting conversations.
- Believing other people can anticipate your needs/read your mind.
- Expecting others to fill your needs automatically, without your asking.
- Not honoring the physical/emotional space of others-forcing self on another.
- Self-abuse-poor diet, insufficient sleep, overworks.
- Sexual, physical, and emotional abuse and neglect.
- Using chemicals/compulsions to avoid personal issues.
- Shaming others- 'You can't really feel that way!', 'You should have known better,' 'all men are insensitive,' 'Women are too emotional.'
- Violating confidentiality.
- Triangulating a third person to send information to a second versus direct communication. (societal problem of expression of feeling)

*Adapted from several sources, including Learning to Say No, Carla Wills-Brandon. 1990*

# Family Systems

## Family's Response to Terminal Illness and Death

A terminal illness and death impact the whole family system, including the roles and the rules of the family.

### Family Roles

The terminal illness and death of a family member requires changes on the entire family system as its members adjust to a painful new reality. The already difficult period of adjustment is usually made even more troublesome by the need for each member of the family to assume roles and responsibilities that need to be filled because the family member is ill or has died. As the family reorganizes, a great deal of stress is experienced, particularly if the family has rigidly defined roles.

- The amount of disruption can be predicted by:
- The position of the dying or deceased family member. (I.e. wage earner).
- The number and type of roles held by the family member. (I.e. cook, communicator, social planner or peacemaker). Family members may want the dying person to continue to fulfill these roles even if he/she is too ill to do so.
- The ability of family members to perform tasks essential to the continuity of family life.
- The degree of scapegoating. Families may use energy to deal with problems created by the scapegoat rather than focusing on its own dysfunctional pattern of behavior.

### Family Rules

Each family, like any other group, has rules governing how its members act, what they are allowed to say, and what kinds of relationships they are permitted to have both with family and with the outside world.

## Open and Closed Families

Families can be thought of as a system that is either open or closed.

**Open systems** acknowledge family rules and allow them to be discussed and altered as necessary. Rules that are common to open family systems are: feelings are important; we can work it out; you are a special person. Terminal illness and death require changes in family rules. The more open family systems are, the better they are able to adapt.

**In Open Family Systems**, change is inevitable; supportive relationships are allowed outside of the family; communication is in a clear, direct way; rules are flexible to meet the needs of individual family members.

**In Open Family Systems**, self worth is primary and performance is secondary; actions represent one's beliefs; and change is seen as normal.

**Closed systems** prohibit any discussion or acknowledgement of family rules. Closed system rules often interfere with a family's adjustment. Rules that are common to closed family systems are: do not raise your voice; do not talk about \_\_\_\_\_'s illness or death; children must be protected from painful experiences, (i.e. funerals); to ask for what I want is selfish; never make mistakes; we cannot talk about or acknowledge our family secrets; crying and other emotional displays are signs of weakness; someone is always to blame.

**In Closed Family Systems,** members are resistant to change; they are extremely private; there is difficulty communicating in a clear manner; and they tend to live by rigid, unspoken rules.

**In Closed Family Systems,** self worth is secondary to power and performance; actions are subject to the whim of the "boss"; and change is resisted.

# Levels of the Family

Families operate on the following three levels:

**Nuclear family** is the group of people that live with the patient. This family is defined by the patient and may not be what we traditionally think of as the nuclear family. Generally, the nuclear family includes the people most important to the patient and most responsible for the patient.

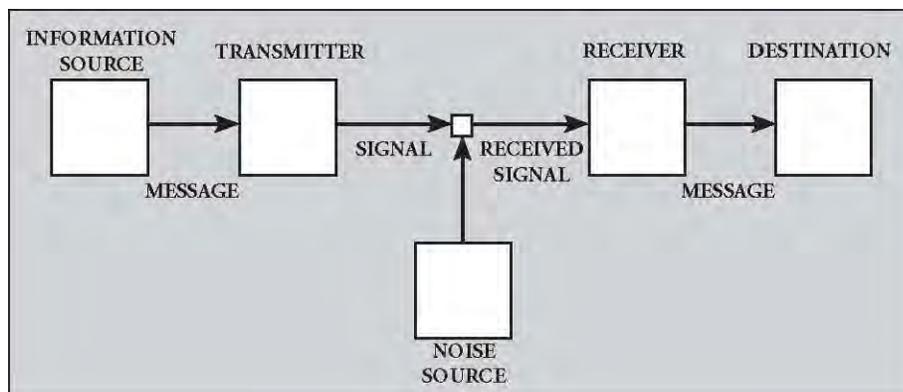
**Extended family** consists of outlying members of the patient's family. Generally, extended family members are aunts, uncles, grandparents, and others involved with the family in a more indirect way.

**Social Network** means friends, co-workers and other people of significance to the family.

All of these individuals play an important role in the life of the patient, and need to be recognized as a part of the team.



## Communication Techniques



To listen to another soul in a condition of disclosure and discovery may be almost the greatest service that any human being ever performed for another. As a Hospice volunteer, you are often in the position to listen to the innermost feelings and fears of patients and family members.

Because communication is such a vital part of the Hospice philosophy, it is important to know how to effectively communicate with patients and family members.

As a first step towards open and effective communication, volunteers should strive to develop an atmosphere of empathy and trust, and accept the patient and family unconditionally. Patients and families should be encouraged to express their feelings, values, beliefs, and attitudes without judgment. They should be allowed to make mistakes without experiencing rejection. Their experiences should be viewed from their perspective. They should be allowed to set the standards and the boundaries of conversation.

Providing an environment conducive to open, empathic relationships are not always easy. The following information regarding communication skills, barriers to communication, and hints for building strong communication is designed to help volunteers learn new and effective ways to interact with Hospice patients and families.

## Communication Skills

There are two types of communication: non-verbal and verbal.

Non-verbal communication includes body gestures, facial expressions, posture, body movements, and dress.

Verbal communication is spoken, encourages and identifies the needs of the patient.

In active listening, the volunteer should act like a sponge absorbing the thoughts and feelings of the patient.

With active listening, the receiver of the message tries to understand what the sender is feeling; and the receiver then puts this understanding into his/her own words and returns this understanding for the sender's verification. The sender does not send a message of his/her own, such as a question, giving advice, expressing feelings, or giving an opinion.

In communicating with a patient in a wheelchair or lying in a bed, it is best to squarely face the other person (sit down to his/her level); adopt an open posture; lean forward; verbally follow the topics; maintain eye contact; and be relaxed.

## Open / Closed Responses

**Small Talk** allows you and the Hospice patient to use open-ended questions as a means to engage in and maintain conversation.

In a role play with other volunteers, brainstorm and write down a couple of open-ended questions that might work in the following situations:

- You are meeting a patient for the first time. The primary caretaker and the nurse just left the room, leaving you alone with the patient for the first time.
- You are volunteering with a patient that you have met several times before, and the patient begins to cry.
- The patient asks you to move so that "Bob" can sit where you are sitting. There is no "Bob" in the room.

- A patient doesn't speak English. You can tell he/she is agitated and no one is around to translate for you.
- You have not had a good experience with one of your patients. He/she begins yelling at you. However, his/her accent makes it difficult for you to understand what he/she is saying.
- You interrupt a patient who is clearly practicing a spiritual activity that is unfamiliar to you and your religion.
- You have met the patient's daughter every time you are with the patient. The daughter tells you to watch out for her brother indicating that he is worthless and not trustworthy.
- The patient asks you for a description of heaven.
- It is clear that the husband of the patient is in charge of ALL family affairs. The man's wife is our patient and she tells him that he has no business telling her what to do, now or ever!
- The patient tells you that you should leave the room and never come back.
- The patient asks you to help him/her pack his/her bags to go to the airport.
- The family wants you to assure them that the patient is not going to die.
- You are having a terrible, horrible, no-good, very bad day. A patient says something that really angers you.

# Exploring the Meaning of Spirituality

adapted from: "Spirituality for Dummies"

## Knowing how spirituality differs from religion

Although religion and spirituality are sometimes used interchangeably, they really indicate two different aspects of the human experience. You might say that spirituality is the mystical face of religion.

Spirituality is the wellspring of divinity that pulsates, dances, and flows as the source and essence of every soul. Spirituality relates more to your personal search, to finding greater meaning and purpose in your existence. Some elements of spirituality include the following:

- looking beyond outer appearances to the deeper significance and soul of everything
- love and respect for God
- love and respect for yourself
- love and respect for everybody

Religion is most often used to describe an organized group or culture that has generally been sparked by the fire of a spiritual or divine soul. Religions usually act with a mission and intention of presenting specific teachings and doctrines while nurturing and propagating a particular way of life.

## Religion and spirituality can blend beautifully

Different religions can look quite unlike one another. Some participants bow to colorful statues of deities, others listen to inspired sermons while dressed in their Sunday finery, and yet others set out their prayer rugs five times a day to bow their heads to the ground. Regardless of these different outer manifestations of worship, the kernel of religion is spirituality, and the essence of spirituality is God or the Supreme Being.

Spirituality is:

- beyond all religions, yet containing all religions
- beyond all science, yet containing all science
- beyond all philosophy, yet containing all philosophy

Loving and respecting all religions and images of God doesn't mean that you have to agree with all their doctrines. In fact, you don't even have to believe and agree with every element and doctrine of your own religion! This goes for any teachings you may encounter along your path. Everybody thinks that what they are doing is right. That's what's so fun about the world. Everybody is doing something different, and each one believes deep in his/her soul that what he/she believes is right — some with more contemplation and conviction than others.

## Understanding the Needs of a Hospice Family

Spiritual care is a major component of the Hospice approach to providing for the needs of the terminally ill. This concept has never been disputed since the very beginnings of Hospice.

Exactly how to go about providing spiritual care for individuals from widely differing backgrounds and ideologies does present more of a challenge.

It's important for Hospice care providers to have a basic understanding of what spirituality is and what spiritual needs are likely to arise as the person faces death.

Spirituality, by its very nature, is difficult to quantify. It's easier, initially, to approach it from the angle of what it is not.

Spirituality is not morality. Morality is an instilled set of social mores, an inner yardstick for measuring what is good for the society in which the individual functions. Sometimes what is immoral in one society may be perfectly accepted in another. A person may experience spiritual pain if his/her behavioral choices are in conflict with his/her moral code, but morality and spirituality are not synonymous.

Spirituality is not psychology. Psychology deals with the emotions, with human relationships and how they function. Psychological problems can cause spiritual pain, but psychology is not spirituality. Spirituality deals with the "why" of life, not the "how".

Spirituality is not religion. It is here that some Hospice caregivers become confused about exactly what they are expected to provide to the dying person. Religious systems have attempted to address spiritual needs while providing moral structure. Sometimes these religious systems have succeeded in enhancing spiritual growth, sometimes they have inhibited it.

## **If spirituality isn't morality, psychology, or religion, what is it?**

Spirituality could be described as transcendent values versus human limitations. Human limitations are those things that "chain us to the earth," the practical, everyday tasks such as paying bills, changing the flat tire, folding the laundry, etc. Spirituality encompasses those things that are above human limitations, such as faith, hope, loyalty, and love. The world of the physical is not an enemy of the soul; rather the choices we make in the real world (such as how we dress, what we spend our money on, etc.) reveal something about our spiritual values.

Spirituality is characterized by questions rather than answers. The physical world can be quantified, measured, and judged. It relies on scientific proof for validation. There are no such parameters for the spiritual. It has been said, "The things that mean the most in life can't be proven."

One job of the human spirit is to seek purpose and meaning on an individual level. No one can accomplish this task for another. Each individual's story will be different, fashioned and shaped by his/her unique experiences in life. Questions arise based on this need to clarify the meaning of one's existence. Who am I with all the distractions of life stripped away? What have I contributed to the lives of others? What do I fear? What do I value?

What if I have a different religious belief system than my patient? Can I still provide spiritual care to them?

Absolutely. It is not necessary that you personally subscribe to the patient's particular belief system in order to offer spiritual support. What is necessary is that you treat the patient's beliefs with the utmost respect and honor.

Each Hospice patient will need to find meaning within his/her concept of the “big picture” of life. Inner peace comes from seeing oneself as part of a “big picture” that makes sense and that one has faith in. It is important that you, as a Hospice spiritual care provider, develop a basic understanding of the patient’s “big picture” so you can support him/her in it, especially if performance of certain rituals or practices are necessary for the patient to be in harmony with his/her belief system.

# Dying Process - Death

## Dying Process, Grieving, and Bereavement

During the weeks or days leading to the patient's dying process, you will be able to comfort the patient by holding his/her hand and by giving the family or caregiver support. Visits by Hospice of Southwest Iowa staff will be more frequent as the patient's condition deteriorates.

The staff will attend to the patient throughout the dying process as long as staff has been informed of changes by the family. If the death occurs at night, and the caregiver is unaware, a nurse will respond as soon as HSI is informed. The volunteer can be of assistance during and after the death by providing support and comfort e.g. making snacks and coffee at the home. For closure to the relationship, the volunteer may need to say his/her goodbye by attending the visitation, funeral, or memorial service. The family appreciates your presence. You are invited to attend the annual memorial service honoring the patients who trusted our care and for whom we grieve.

## Tasks of the Dying Patient

Oftentimes, when a patient is in his/her final days, the family may perceive that the loved one is withdrawing from the family by not talking as much or taking interest in family matters. Families are reassured that their loved one still loves them and is interested, however he/she now needs to focus his/her energy and efforts on the dying process.

For someone who is facing the final days, there are several important tasks that need to be addressed. These tasks of the dying patient are as follows:

- Deal with discomfort, incapacitation, and other symptoms of the illness.
- Develop and maintain adequate relationships with caregivers. The patient may feel insecure about expressing honest concerns, feelings, or needs.
- Preserve a reasonable emotional balance by managing upsetting feeling aroused by the illness, such as anxiety, anger, alienation, inadequacy or guilt.
- Preserve self-image and maintain a sense of mastery. Losses must be grieved; goals and expectations must be readjusted. The patient must define the limits of independence and find a personally and socially satisfactory balance between accepting help and taking an active/responsible part in his/her life.
- Preserve relationships with family and friends despite isolation and alienation.
- Prepare for an uncertain future in which significant losses are threatened. Grieve for current and potential losses.
- Arrange a variety of affairs; pain, discomfort, anxiety, fear, confusion, or disability may hinder a patient's ability to complete these tasks.
- Complete the five "gifts" (or tasks) of relationships:
  - “I love you”
  - “Please forgive me”
  - “I forgive you”
  - “Thank- you”
  - “Good-bye”

# Emotional Reactions of Dying Patients and Their Families

When we face the end of our lives, we have a variety of emotions that are present and may, at times, over-whelm us. Families also experience their own distinct emotions, feelings, and behaviors that result from their fear of losing their loved one, coping with difficulties, or adjusting to the changes of roles in the family structure. Some of these emotions and feelings may include:

- Anxiety Fear of the unknown
- Fear of loneliness
- Fear of loss of family and friends
- Fear of loss of self-control
- Fear of suffering and pain
- Fear of loss of identity
- Fear of sorrow
- Fear of regression
- Depression
- Anger and Hostility
- Guilt and Shame
- Acceptance
- Bargaining
- Denial

## Loss

As a Hospice volunteer, you can assist patients, families and friends to recognize and verbalize their losses.

- View the loss from the griever's unique perspective.
- Do not try to explain the loss in religious or philosophical terms too early. To say "It's God's will" or "Everything happens for a reason", will not be helpful when grievers need to ventilate their feelings and anguish. Later such explanations may assist the grievers to find some meaning and gain perspective in their loss.
- Do not suggest the griever should feel better because there are other loved ones alive. This robs the griever of legitimate sadness.
- Help the griever to recognize, actualize, and accept the loss. Assist the griever to come to an intellectual acceptance of the loss. Facilitate life review and discussion of the loss.
- Allow the bereaved to cry and cry, talk and talk, review and review without interruption of your sanity. This is a necessary part of the process, especially in the early stages of grief. Do not close it down. Each story told, each memory relived, each feeling expressed represents a tie to the deceased that the griever must process by remembering, feeling the emotions generated by it, and then letting them go. Encourage this expression.
- Do not be surprised if the griever talks about the same issues repeatedly.
- Do not be afraid to mention the lost person to the griever.

- Help the griever to identify current and potential secondary losses (physical and symbolic) resulting from the death. Often these secondary losses are more difficult to resolve than the initial loss.
- Assist the griever in recognizing that not only must he/she grieve for the deceased individual, but also for the dreams, fantasies, and expectations that he/she had for and with the deceased. These need to be identified and grieved as well. They are often not recognized because they are not tangible. New issues will arise through the developmental cycle.

## Grief Process

**Grief:** The process of experiencing the psychological, social, and physical reactions to your perception of the loss. This definition has 5 important implications:

- Grief is experienced in each of three major ways-psychologically, socially, and physically.
- Grief is a continuing development, involving many changes over time. It will come and go and appear at different times.
- Grief is a natural and expectable reaction.
- Grief is the reaction to all kinds of losses, not just death.
- Grief is based upon your unique, individualistic perception of the loss. It is not necessary for you to have the loss recognized or validated by others for you to experience grief.

**Mourning:** The term refers to conscious and unconscious processes that:

- gradually undo the psychological ties that bound you to your loved one
- help you adapt to the loss
- help you to live in a new world without the lost object (person, place, or thing)

**Bereavement:** The state of having suffered a loss. To be bereaved means that you have suffered a loss.

*Adapted from How to go on Living When Someone You Love Dies by Therese Rhando. 1991, pp.11-12 Bantam Books: New York.*

**Anticipatory Grief and Mourning** are responses to the expectation of death or loss.

**Postmortem Grief and Mourning** are responses to the reality of that death or loss.

# Normal Grief Reaction

Feelings	Thought Patterns
Sadness Anger Guilt, Self-Reproach Anxiety Loneliness Helplessness Shock Yearning Relief Numbness Despair Hopelessness Bitterness	Disbelief Confusion Preoccupation Sense of Presence (of the deceased person) Lack of Concentration Lack of Self-Esteem Repeated Review of the Loss Event Increase (or Decrease) of Dreams Search to Understand Implications of the Loss A Sense of Depersonalization (“I walk down the street and nothing seems real, including myself.”)
Physical Sensations	Behaviors
Hollowness in the Stomach Tightness in the Chest Tightness in the Throat Oversensitivity to Noise Shortness of Breath Weakness of Muscles Lack of Energy Dry Mouth Rapid Heartbeat Muscle Tension Fatigue Decreased Resistance to Illness	Sleep Disturbances Appetite Disturbances Absent-Minded Behavior Social Withdrawal Dreams of the Deceased Avoiding Reminders of the Loss Searching, Calling Out Sighing Crying Visiting Places or Carrying Objects that Remind of the Deceased Treasuring Objects that Belong to the Deceased Increase or Decrease in Activity

## Manifestations of Grief

- Anger at Self, Doctors, God, etc
- Guilty feelings
- Sleep disturbances
- Appetite changes
- Feelings of not being understood
- Feelings of abandonment
- Feelings of being smothered
- Purchase of unneeded items
- Thoughts of selling everything & moving
- Physical ailments
- Unbearable loneliness & depression
- Chronic irritability
- Crying for no apparent reason
- Obsessive thoughts of the deceased
- Panic over little things
- Withdrawal from social interaction
- Anger at being left alone
- Lack of concentration

# Basic Facts About Grief

- Grief is unavoidable & must be experienced
- Grief is cumulative
- Verbalization speeds up grieving
- Grieving people do not need advice or insensitive questions
- Grief feels like a roller-coaster ride which lasts an indefinite period of time
- The quiet presence of a friend can help
- Complicated grief can be lengthy & intense
- There is no right or wrong way to grieve
- Lengths & intensity depend on a number of variables

## Phases of Grief

**The Avoidance Phase:** Shock, denial, disbelief.

Statements:

- I can't believe it!! John can't be dead!!
- You've made a mistake.
- No! No! No!
- Oh help me. I will not survive!
- I can't feel anything. This must be a dream.

**The Confrontation Phase:** a highly charged emotional state in which you repeatedly learn that your loved one is dead and in which your grief is more intense, with reactions to your loss being felt acutely.

Statements:

- I feel like part of me has died with her.
- Nothing means anything to me anymore. Not life, not work, not God-nothing!
- If only I could have persuaded her to go to the doctor sooner.
- All I want is my baby back. Damn you for not bringing her back to me!
- Finally, it is over. I could not take much more of this illness. I feel bad but I could not have endured much more.

**The Accommodation Phase:** gradual decline of acute grief and the beginning of an emotional and social re-entry into the everyday world in which you learn to live with your loss.

Statements:

- I surprised myself when I heard myself laughing. It had been such a long time.
- Sometimes I feel guilty if I am not in pain over my brother's death anymore.

*Adapted from How to go on Living When Someone You Love Dies by Therese Rhando. 1991, pp.11-12 Bantam Books: New York.*

# Strategies to Help a Grieving Person

- Give the person permission to grieve. Grief is not a weakness. It is the necessary price of caring.
- Accept whatever thoughts, feelings, and behaviors the bereaved is feeling. Everyone's grief is unique. Be non-judgmental. Try to view the loss from the bereaved person's perspective.
- Tell the person about normal grief. Knowing what is normal, is re-affirming to someone who doubts the normalcy of his/her experience. Offer hope by expressing your belief in the capacity to heal.
- Encourage the person to think and talk about the loss. Practice listening. Assist the bereaved to take memory trips. Look at photo albums. Go places that hold particular meaning, such as a special room in the house or facility or grave site, a park. Ask questions about the relationship, individual or role:
  - What was \_\_\_\_\_ like?
  - How did you meet?
  - What was the first memory you have of him?
  - What was it like raising a family together in the 19\_\_'s?
- Allow the person to cry. Crying is the valve on an emotional pressure cooker. It is healing.
- Touch the person. Persons in grief often express a physical emptiness and a desire to be touched and hugged. Where words are inappropriate and empty, touch can speak volumes.
- Allow as much environmental control as possible. People in grief feel that they have lost control of their lives. Providing opportunities for some level of control helps in affirming self-esteem and a capacity for decision making.
- Share what you are gaining from interaction with the bereaved person. Sharing affirms that you are interested in him/her as a person and that he/she is giving you something of value.
- Assist the person with necessary tasks. Grieving takes energy, and assistance with the activities of daily living may be necessary.
- Encourage involvement in activities. Loneliness is a passive state that is offset by activity and social contact. Be alert to each person's individual need to determine his/her level of involvement. Gentle encouragement repeated over time is helpful. Provide opportunities for the bereaved to help others.
- Provide information about community resources. Support groups, chore services, and legal aid may offer needed assistance.

*Focus on Geriatric Care and Rehabilitation. Volume 4, Number 1, May 1990.*

# Bereavement Volunteer

## Ten Ways to Express Your Sympathy

“My world collapsed the day my husband died of lung cancer, and I found myself among the newly widowed. I was too numbed by shock and grief to answer those who said, ‘If there is anything I can do, let me know.’ Without waiting for an answer, many friends found an amazing variety of ways to express their loving concern.”

“By comparing notes with others who have experienced such a loss, I have learned that there are many ways to help convey the message, ‘I care’.”

### **1. Look for an immediate need and fill it.**

The first few days are filled with many things you can do. Offer to answer the telephone and to call those who need to be notified, meet incoming relatives at the airport, train or bus depot; offer a spare room to an overnight visitor; provide transportation as needed; if there are children in the family, offer to baby-sit or take them out while funeral arrangements are being made, arrange with the family to stay at the funeral home when a host is needed. When my husband died our family was too far away to be with me immediately. One couple arrived within minutes of my phone call and stayed with me for the next few hours. Another friend came to spend the night. As time passed relatives and friends took turns spending days with me so that I could gradually adjust to being alone.

### **2. Provide food.**

I am not even sure why the thought of preparing a meal seemed like a Herculean task at this time, but it does. After my husband died, it was with relief and gratitude that I welcomed the casseroles, salads and desserts that people brought.

A young man who was left with three small children said, “The food friends and neighbors brought was a lifesaver. There was enough left to put in the freezer for those nights when I came home from work faced with getting dinner for four. Friends and neighbors brought me food until I was able to find a housekeeper.

When taking food to someone’s home, mark your dish so that it does not get lost. Then go back later and pick it up so that the family will not need to be concerned about returning dishes. It is even easier if you deliver your contribution in a container that can be discarded.

### **3. Send flowers or donate to a favorite charity.**

When friends say “No flowers,” consider sending a planter, terrarium or potted plant to the home. A few weeks later, a single rose, a few flowers from your garden or a small bouquet from a roadside stand can brighten the day for your friend and show that you care.

A green thumb shows limitless possibilities. One woman I know was grateful when her neighbor, an avid gardener, volunteered to keep some of her orchids in his greenhouse while she went away.

#### **4. Reach out and touch.**

Many people have a need-whether they recognize it or not-to be touched during a difficult time. People who are grieving can be greatly comforted by a kiss on the cheek, a warm hug or a handclasp. It's amazing how simple touch can communicate when words fail.

#### **5. Listen.**

Listening can be one of the best ways to help a person work through feelings of grief. Most people's initial reaction to the death of loved one is shock. There is a need to talk about the loss. Unexpressed grief can lead to prolonged depression. I will always cherish the card that a friend sent with the words, "If talking helps, I am only a phone call away."

One minister cautions "Do not be afraid of causing tears by encouraging a friend to talk. Crying expresses grief in a normal way. Above all, be sensitive to the mood of the bereaved family." While there are many times they may want to talk about their loss, there are other times that they may appreciate the silence. Sharing the silence is another way of listening.

#### **6. Send a note or make a phone call.**

When you call or write you do not need to say very much to make your feelings known. A simple, "We love you" speaks volumes. A condolence letter is easy to write if you keep a few special things in mind. It can be comforting to recall a shared event such as a dinner or a picnic, or a special quality of the deceased. "We did so enjoy your mother's sense of humor," for instance, or "There will never be anybody with John's ability to..." or "Sally was the only woman any of us knew who could..." These can be light or serious, anything from growing tulips to making people laugh to doing needlepoint. It is the "something special" that stands out in your mind about that person.

#### **7. Encourage the bereaved to get out of the house.**

On several occasions, I was invited out to lunch or dinner and welcomed the opportunity to get out of the house and to be with friends. Many people were especially sensitive to the times when I had been alone for a few days. They would call and ask, "Do you still have company?" If the answer is no, they would say, "We would like you to go to dinner with us. We will come and pick you up."

#### **8. Give of your talent and experience.**

On the day following my husband's death our household plumbing chose the most inopportune time for a massive case of total malfunction-kitchen, bathroom, laundry, the entire house. I frantically called a plumber friend for a referral. He said, "Don't worry; I will come over myself". I will be forever grateful to him and another friend who worked most of the day to get things functioning before out of town relatives began to arrive. When the wife of a friend of mine was killed in a car crash, he needed legal advice and was most grateful when an attorney he knew donated his services.

#### **9. Help in the days ahead.**

Too often a person who has lost a loved one is surrounded by relatives and friends for a week or so, and then the house is empty. It is when people have swung back into their daily routines that friends are needed most-grief and loneliness last for many months.

## **10. Remember to stay in touch.**

See your friend more often than you did before, perhaps for lunch, shopping, museum outing, or movie. Week-ends and holidays are especially difficult; these are times when others are apt to be busy with their own families. Make a special effort to include the bereaved friend in your family activities.

Encourage the person to become active again. This may mean painting the garage with the bereaved, helping with a hobby or encouraging your friend to pick up a sport again.

By being more realistic about death, we live more fully ourselves. To help our friends and relatives work through their grief in a healthy and constructive way is to help them get back into the mainstream of productive living.

*Adapted from material shared by Riverside Hospice – New Jersey*

# Worden's Tasks of Mourning: Task I

## Task I: "Accept that the loss is real".

Come to full realization the loved one is gone.

- Part of acceptance is to come to believe that reunion is impossible in this life.

Ways grieving people may hinder this task:

- Leave loved one's belongings exactly the same as if the person will be back to use them again (Mummification)
- Deny the meaning of the loss. They may make loss seem less significant than it actually is.

May say things like "I Don't Miss Them", "We Weren't Close", "He Wasn't a Good Father". They may get rid of all artifacts that would bring them face to face with reality.

Coming to realize the loss takes time.

# Worden's Tasks of Mourning: Task II

## Task II: "Deal with the distress that bereavement causes."

Work Through to the Pain of Grief

- Society gives messages that aren't helpful for bereaved: "You don't need to grieve, you are only feeling sorry for yourself."

Task II can be short-circuited by denying the pain of the loss, idealizing the dead, avoiding reminders of the deceased, using alcohol/drugs; all of these keep the bereaved from accomplishing Task II.

# Worden's Tasks of Mourning: Task III

## Task III: "Engage in a world in which the person who died is absent."

Adjusting to environment in which the deceased is missing.

For many widows/widowers it takes a considerable amount of time to realize what it is like to live without their spouse. Usually around 3 months after the loss, the realization begins.

Some of the issues that go along with this task are to:

- realize all the roles the person played in their life
- adjust to who they are without the deceased
- new identity
- meaning in life after loss

- Not adapting to new roles
  - Withdrawing from the world
  - Promoting their own helplessness
  - Not developing skills to cope with loss and changing roles

## Worden’s Tasks of Mourning: Task IV

### Task IV: “Emotionally relocate the deceased and find ways to memorialize the person.” (2002 revision)

Emotionally relocate deceased & move on with life.

- Doesn’t mean trying to forget the relationship
- Incomplete Task IV would be described as not loving
- Holding onto the past attachment, then going on and forming new ones.
- Some find loss so painful they may make a pact with themselves to never love again.

### How do you know when mourning is finished?

- Able to think of deceased without pain. There may always be a sense of sadness but not wrenching pain as initially.
- When the grieving person can reinvest their emotions back into life and in the living.
- Regain interest in life.
- Feel more hopeful.
- Experience gratification again.
- Adapt to new roles.

## Children / Teen Grief

### Do’s and Don’ts

Do involve the children. They are part of the family.	Don’t tell a child the person died because God wanted them in heaven. Blaming God may create future spiritual problems.
Do let the children know they didn’t cause the illness or the crisis. God shares our pain and will help us get through. Answer questions honestly and be specific.	Don’t say someone died because they were old. To a small child, anyone over 20 is old. They may think mom or dad is next.
Do allow children to say good-bye through expression of their love to the person dying, attending funeral if they want to attend, visiting the cemetery.	Don’t hide your grief from children. Seeing you grieve will help the child know it is normal to cry.
	Don’t tell a child the person is sleeping. The child may be afraid to go to sleep.

# Age-Specific Responses about Death

## Birth to 2 Years

Sense of loss and reaction to it. Child will sense the distress of the parent and a change in the emotional atmosphere of the home.

## Ages 3 - 5

Death is seen as a separation; not final; can be reversed. Very limited death concept. Death means less active.

## Ages 6-11

Death is controlled externally; can be avoided; may have been caused by bad behavior; "magical thinking."

## Ages 12 - 18

Death is inevitable, but only for 'old people'. Won't happen to me.

## Warning Signs of Grief in Children

- Extended period of depression in which the child loses interest in daily activities & events
- Inability to sleep, loss of appetite, prolonged fear of being alone
- Acting much younger for an extended period
- Excessively imitating the dead person
- Repeated statements of wanting to join the dead person
- Withdrawal from friends
- Sharp drop in school performance or refusal to attend school

## Adult Grief

### What People Need During Grief

- Time
- Rest & relaxation
- Security
- Hope
- Caring
- Goals
- Small pleasures
- Permission to take a step back

# Bereavement Services That May Be Provided by Hospice

- Individual visits
- Bereavement professionals & volunteers
- Mailings
- Memorial Services
- Support Groups
- Referrals to community resources
- Other special projects & events

## Ideas for Caring Actions

### Immediately After the Death:

- Accompany the bereaved to the funeral home, cemetery, or on miscellaneous errands.
- House-sit during the funeral or if the survivor needs to leave town.
- Offer a place for out-of-town guests to stay.
- Help with the phone by: making phone calls to relatives and friends, answering phone calls.
- Help with the car and transportation: pick up people from the airport, transport children to school or activities, wash the car or fill it with gas.
- Help with clothing by: taking care of laundry, polishing shoes, delivering and picking up dry cleaning.
- Help with pets by: overseeing feeding, car and exercise; taking them to the vet.
- Help with the bereaved children by: offering to baby-sit, providing transportation, reading a story, taking them on an outing.
- Help around the house by: mowing the lawn, shoveling snow, offering to tidy up the house, offering to wash linens for guest beds.

### Anytime After the Death:

- Write a note/send a card
- Call on the telephone
- Help with writing tasks (assisting with 'Thank you's', addressing envelopes, and making a list of people who phoned or sent food.)
- Send flowers, a plant, or take a flower from your garden.
- Telephone before going to the grocery shopping to check for needs.
- Invite them to your home for dinner or take in food.
- Give them a book by their favorite author or a tape or CD of your favorite music.
- Send comforting and inspirational news clippings or a comforting poem.
- Go to the cemetery with them.
- Offer to assist them with errands.
- Buy two tickets to anything and invite the bereaved to join you.
- Give them a date when you will take them out for lunch.
- Get information on local support groups.
- Remember their birthdays, holidays and other special times.

*Adapted from "Grief Counseling and grief therapy: A Handbook for the Mental Health Practitioner", 2nd edition; J. Wm Worden, 1991, 2002, "The Task-based Model"*