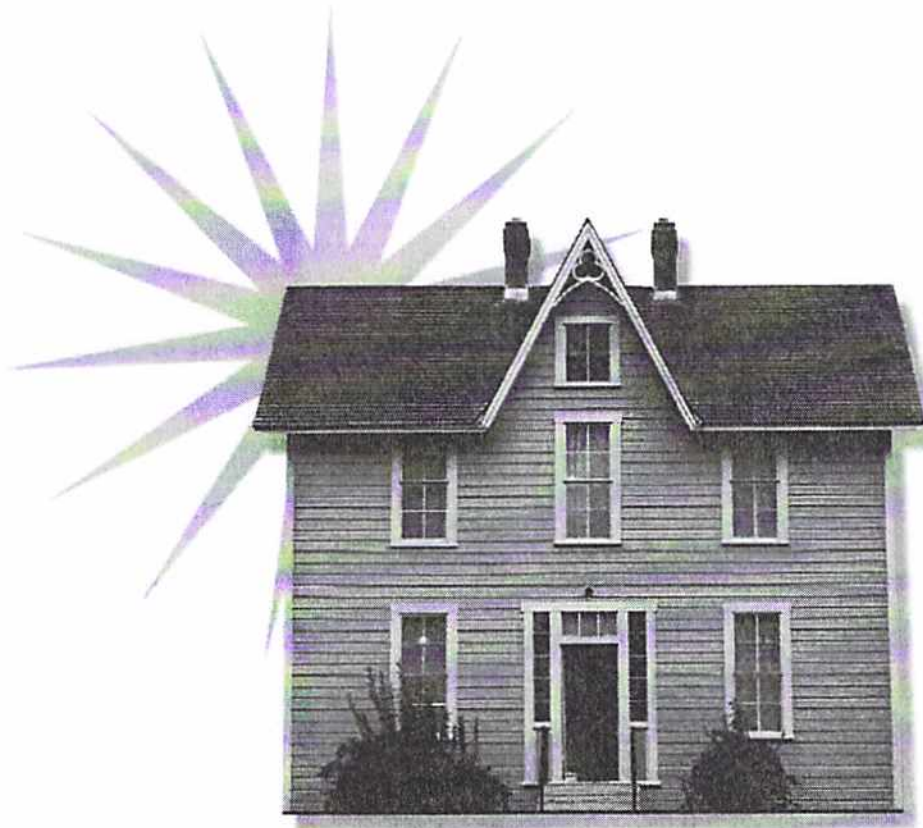


# SELF-LEARNING IN-SERVICE PACKET



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## Compassionate Care

*Committed to Quality of Life*

## **PHILOSOPHY**

Hospice care affirms life. It is a concept of care, rather than a place. This type of care specializes in providing comfort through skillfully managing the patient's symptoms. The care focuses on enhancing the quality of life while neither hastening nor prolonging the quantity of life.

Hospice provides a comprehensive range of professional and supportive health care, addressing the palliation of physical, psychosocial and spiritual pain and other symptoms caused by the terminal disease process. This team of caregivers coordinates their interdisciplinary efforts in meeting the needs of terminally ill patients and their loved ones.

## **COMPASSIONATE CARE HOSPICE'S MISSION**

The mission of Compassionate Care Hospice is:

- To provide the highest quality hospice care in the most cost effective manner
- To give dignity to the dying experience
- To provide access to care for all persons
- To educate the community

## **GOALS**

The goal of the Hospice/nursing facility program is to provide the best possible care for the patient with life-limiting illnesses by:

- Working with the nursing facility's staff to achieve optimal pain and symptom control management
- Collaborating with nursing facility staff regarding the resident's care needs
- Providing specialized ongoing training and education for nursing facility personnel concerning care of the terminally ill and family issues related to death and bereavement
- Addressing the physical, emotional, social and spiritual needs of the residents and their families

## WHO WE CARE FOR

Compassionate Care Hospice cares for any resident who is suffering from a life-limiting illness. The term “life-limiting” refers to any illness that has progressed to the point where the physician estimates a prognosis of 6 months or less.

Medicare/Medicaid and the National Hospice Organization provide guidelines to help determine when a resident is hospice appropriate.

**Some examples of diagnoses that may be considered hospice appropriate are patients in end stages of:**

- Cancer
- AIDS
- ALS (and other neurological diseases)
- Alzheimer’s disease (stage 7)
- Cardiac disease
- Lung disease
- Renal disease
- Liver disease

**\*\*\* Hospice patients have chosen palliative care rather than curative.**

## HOSPICE CRITERIA

Some general criteria that Compassionate Care Hospice uses in assessing hospice appropriateness are:

- Patient and family desire comfort care only
- Progressive decline in patient activity and functional status
- Multiple hospital admissions for symptom control
- Several secondary diagnoses
- Decline in nutritional status
- Documented evidence of disease progression
- Decreased mental status

## LEVELS OF CARE

There are four levels of care under the Medicare Hospice Benefit

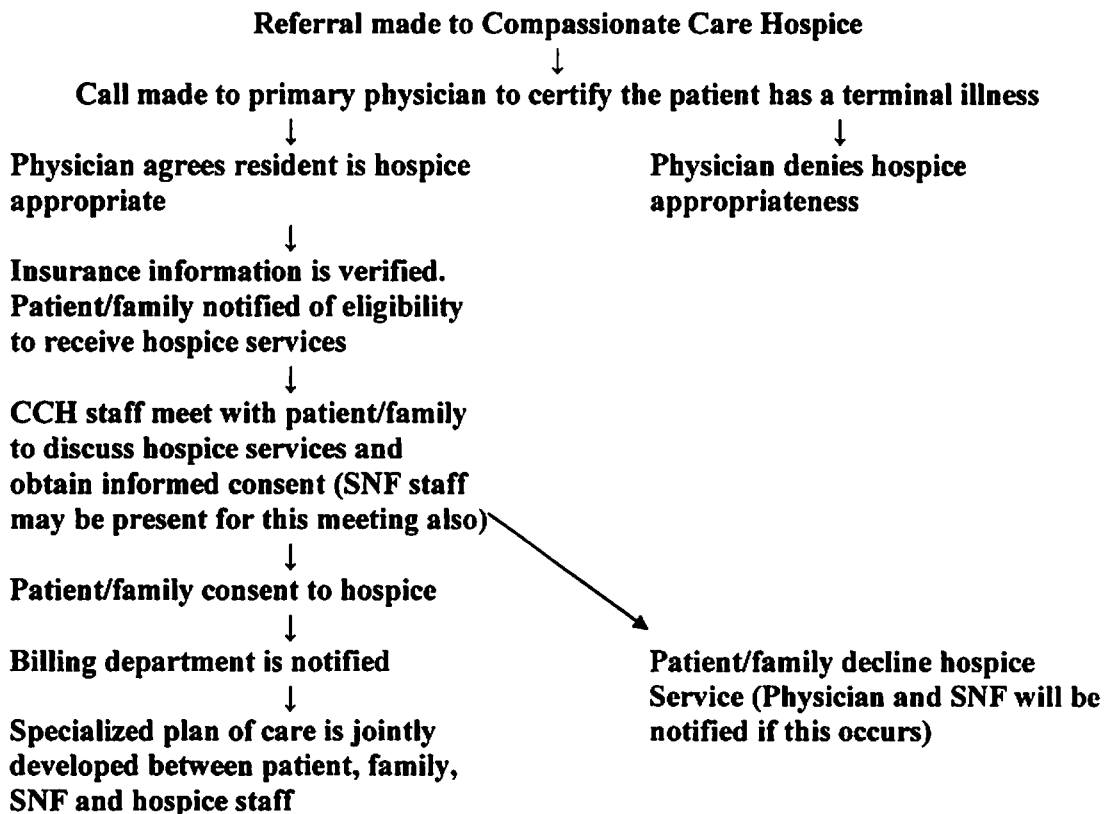
- **Routine:** Traditional level of care received at home or in a nursing facility.
- **Continuous care:** Short term care provided during periods of crisis to maintain the patient at home. Primarily nursing and aide care.
- **Respite:** A period of up to 5 days in which a patient is removed from the home to relieve care givers.
- **Inpatient:** Short term for pain or other uncontrolled symptoms.

## ADMISSIONS PROCESS

*Anyone can refer a resident to hospice!* Family members, physicians, friends, nursing facility staff and even members of the resident's clergy make referrals.

Once a referral is received the hospice admissions staff will contact the patient's primary physician to ascertain if the patient is appropriate. Medical records will be reviewed and the hospice staff will then visit with the resident and family to explain hospice services and to ascertain resident and family wishes.

Our goal is to admit residents to hospice care within 24 hours of a completed referral.



## WHAT WE PROVIDE

- Specialized comfort care
- Medical supplies related to the hospice diagnosis
- Durable Medical Equipment related to the hospice diagnosis
- Medications for pain and symptom management of the hospice diagnosis
- Short term hospitalization if indicated by the hospice plan of care
- Continuous care when indicated
- Family counseling during the illness
- Laboratory and diagnostic services if indicated in the hospice plan of care
- Transportation if indicated in the hospice plan of care
- Physical/Occupational/Speech therapy if indicated in the hospice plan
- Bereavement support to family, residents and staff as needed

## MEMBERS OF THE HOSPICE TEAM

- **Patient's Primary Hospice Physician:** Directs the Care Plan
- **Hospice Medical Director:** Oversees the Care Plan
- **Nursing:** Initiates the Care Plan together with patient, family, SNF staff and members of the Interdisciplinary Team. Coordinates the hospice care. Expert in symptom control and comfort with the terminally ill.
- **Social Workers:** Performs psychosocial assessment on the patient and family. Assesses the patient/family needs and assists with long-term planning, coping, funeral arrangements, accessing additional services appropriate to needs.
- **Hospice Aides:** Provide personal care to the hospice patient and housekeeping duties as directed by the care plan.

- **Trained volunteers:** Provide a variety of tasks for the hospice patient and family such as handholding, reading to the patient, helping prepare meals, friendly visitation and respite for the caregiver.
- **Therapists:** Provide physical, occupational, or speech therapy to hospice patients as indicated in the hospice plan of care.
- **Dietician:** Provides consultation on the special dietary needs of some hospice patients.
- **Counselors:** Work with patients and families to assist with coping, grief work and bereavement care (13 months)
- **Chaplain:** Addresses the spiritual needs and concerns of hospice patients and their loved ones

## **PATIENT RIGHTS**

Hospice patients have the right to be informed of his or her rights, and the hospice must protect and exercise these rights. Compassionate Care hospice complies with federal, State and local requirements in regard of patient rights. At a minimum the patient has a right to:

- Effective pain management and symptom control
- Involvement in developing his or her plan of care
- Refuse care or treatment
- Choose his or her attending physician
- Have a confidential clinical record
- Be free from mistreatment, neglect or verbal, mental, sexual and physical abuse, including injuries of unknown source and misappropriation of patient property
- Receive information about the services covered under the hospice benefit
- Receive information about the scope of services the hospice will provide and specific limitations to those services.

## **COORDINATION OF SERVICES**

The coordination of services is an important process to enhance the care and management of the hospice patient.

### **Expectations**

- Communication regarding the provision of care with facility staff and physician
- Knowledge of the interdisciplinary team member responsible for care.

Information you can expect to receive:

- The hospice plan of care
- Advance directives
- Physician certification and recertification
- Names and contact information of hospice personnel
- Instructions on how to contact hospice on call
- Hospice medications
- Hospice physician orders if pertinent
- All interdisciplinary notes and assessments

## **WHEN TO CONTACT HOSPICE**

Compassionate Care Hospice is responsible for the management of the patient's hospice care and for charges incurred to provide that care. It is for that reason that **IT IS IMPERATIVE TO NOTIFY COMPASSIONATE CARE HOSPICE OF ANY OF THE FOLLOWING:**

- A change in a patient's physical, mental, social or emotional status occurs.
- Clinical complications that suggest a need to alter the plan of care
- A need to transfer the patient from the facility, as the hospice retains responsibility for any continuous care or inpatient care necessary related to the terminal illness
- Patient death

We are available 24 hours a day, 7 days a week. Together we will make a determination with the patient's attending physician as to the appropriate treatment of the patient. If it is agreed upon that a transfer is needed, Compassionate Care will arrange the transport. Please note if the patient has a ***DO NOT HOSPITALIZE*** order on the chart.

**COMMUNICATION IS THE KEY TO PROVIDING THE BEST CARE FOR THE PATIENT**

## **PAIN AND SYMPTOM MANAGEMENT**

Compassionate Care Hospice's mission is to enhance dignity at end of life. Pain and symptom lies at the heart of hospice care. Medical, pharmacological, and complementary therapies may help control a range of debilities that if left untreated reduce the patients will, strength and dignity.

Professional expertise and an individualized plan of care make pain and symptom control possible. The hospice team and facility staff collaborates to improve pain and symptoms so that our patients can function optimally while maintaining dignity.

# DEATH AND DYING

## The Dying process

The dying process begins well before death actually occurs. Death is a personal journey that each individual approaches in their own unique way. There are many paths one may take but only one destination.

There are milestones on this journey but because everyone experiences death in their own way, not everyone will stop at each milestone. Listed below are common milestones

### One to three months prior to death

- Patient may begin to withdraw
- Begin to contemplate life
- Appetite wanes
- Energy level decreases

### One to two weeks prior to death

- Patient may sleep more and become disoriented
- Vital signs decrease
- Increased perspiration
- Skin color changes in response to circulation decrease
- Breathing changes
- Loss of ability to speak

### A couple of days to hours before death

- Breathing becomes more irregular
- Hands and feet may become mottled
- Patient usually unresponsive

**“Death is not extinguishing the light; it is putting out the lamp because the dawn has come”**

Rabindranath Tagore

## DEATH OF A HOSPICE PATIENT

Compassionate Care Hospice is available **24 hours a day, 7 days a week**. As it becomes apparent that a hospice patient is approaching death, Compassionate Care becomes even more present to ensure physical, psychosocial and spiritual comfort. We will be working with the patient, family and facility staff to provide comfort, education and support as the patient proceeds through the dying process.

**If a Compassionate Care Hospice patient passes away while the hospice staff is not present, the facility will notify the hospice of the patient’s death. It is then jointly**

determined if the hospice or the facility will notify the physician, family, funeral home and who will pronounce the patient.

**If necessary, the hospice nurse will visit the facility at the time of death to provide support to the family, other residents and staff as well as to provide the after death care of the patient. If the hospice nurse is present for the death, this will occur immediately.**

Even if your facility wishes to notify the family of the patient's death, the hospice staff will issue follow-up contact soon after the death to offer support and explain the bereavement program. Bereavement services are also available to fellow residents and staff as identified on the plan of care. Closure is important for both the survivors and the hospice staff.

## **INPATIENT LEVEL OF CARE**

General inpatient level of care is available to hospice patients in need of inpatient pain or symptom management that cannot be provided in other settings.

In most cases the decision to change a patient's level of care is based on the clinical condition of the patient. Hospice inpatient requires the documentation of an acute change in the patient's condition, necessitating aggressive, intensive treatment for management of symptoms. Examples include:

### **Pain requiring:**

- Complicated technical delivery of medication requiring RN for calibration, tubing changes, or site care;
- Frequent evaluation by physician or nurse
- Aggressive treatment to control pain and frequent medication adjustment.

### **Symptom changes such as:**

- Sudden deterioration requiring intensive nursing intervention;
- Uncontrolled nausea and vomiting
- Pathological fractures
- Respiratory distress
- Open lesions requiring frequent skilled care
- Complex wound care

### **Psychological and social problems such as:**

- Acute anxiety, fear of dying or depression requiring intensive nursing interventions
- Collapse of family support and patient requires intensive skilled care

### **Patient/Family teaching:**

- Complex treatments or medications

### **Imminent death:**

- Requires skilled nursing care for pain or symptom management.

## **COORDINATION OF CARE AND SERVICES FOR INPATIENT LEVEL OF CARE**

The coordination of care and services is an important process to enhance the care and treatment of the hospice patient.

### **Hospice Responsibilities:**

- Hospice shall evaluate, authorize care and arrange for admission of patients requiring inpatient level of care
- Hospice staff shall coordinate the palliative services provided to each patient by reviewing the plan of care and treatment with the staff. Hospice shall provide a copy of the patients plan of care
- Hospice shall communicate effectively with the facility staff.
- Hospice shall document in the patients record

### **Facility Responsibilities:**

- Facility shall designate an individual responsible for implementation of the written agreement
- Staffing patterns will meet the standard of 24 hour nursing services sufficient to meet the patient/family needs
- The environment will be home-like and promote privacy and comfort.
- Visitors will be permitted 24 hours a day and accommodations will be provided for families to stay overnight.
- All orders, events will be documented and communicated with the hospice team
- On discharge a discharge summary will be completed and hospice will have access to patient records.

## **WHEN TO CONTACT HOSPICE**

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**COMMUNICATION IS THE KEY TO PROVIDING THE BEST CARE FOR THE PATIENT**

## **INFECTION PREVENTION AND CONTROL**

### **Performance Improvement Plan**

#### **I. INTRODUCTION:**

The Performance Improvement Plan for the infection control program reflects Compassionate Care Hospice's mission statement, vision and values.

The Performance Improvement Plan for infection control has been developed based upon the demographics of the population served. The population is diverse and patients may be referred to Compassionate Care Hospice from any area of the state. The demographics reflect a large geriatric population with terminal illnesses, who are immunocompromised and have underlying chronic conditions.

The plan is inclusive of the home care population, types of the infections and pathogens identified, the identified opportunities for improvement, current literature and recommendations from Centers for Disease Control and Prevention (CDC), Community Health Accreditation Program (CHAP), American Association of Medical Instrumentation (AAMI), and the Federal and State standards/regulations.

#### **II. PURPOSE and SCOPE of PERFORMANCE IMPROVEMENT PLAN:**

The purpose of the plan is to provide quality care to the patients served by Compassionate Care Hospice and to perform activities that will reduce the risk of transmission of infection to patients, staff and families. The plan has been established for the purpose of prevention and control of nosohusial infections.

The scope of service incorporates the patients, families, employees, and the community. The scope of service is reviewed annually and is revised according to the needs of all of the above plus quality improvement findings, revised standards and updated knowledge regarding infectious diseases.

The infection surveillance system, educational programs and the development of policies and procedures for the prevention and control of infections is designed to assist all healthcare workers in providing quality patient care.

#### **III. GOALS and OBJECTIVES of the PERFORMANCE IMPROVEMENT PROGRAM**

The goals of the Infection Prevention and Control Performance Improvement Plan are as follows:

To provide the means for tracking and identifying health care associated infections in order to provide information that will assist in determining opportunities for improvement of patient care.

To continuously monitor surveillance data, infection control practices and patient outcomes.

To provide education to all staff members based upon this information, regarding ways to improve the prevention and control processes to reduce health care associated infection rates to the lowest possible level.

To provide an Infection Control program that will protect staff and patients from infections, including but not limited to exposure to bloodborne pathogens, tuberculosis, antibiotic resistant organisms and communicable diseases.

**The objectives of the Infection Control Performance Improvement Plan are to:**

Identify all health care associated infections through total surveillance in order to establish base line data and identify areas for risk reduction. Targeted or focused study will be performed in the event that any infection control problems are identified.

Monitor all culture results to identify patients with multiple drug resistant organisms and other significant organisms so the appropriate precautions can be instituted to prevent transmission. Monitor microbiological trends to identify clusters or outbreaks of infections.

Educate staff regarding general infection control practices, infection rates and opportunities for improvement through methods of prevention, changes in practice as mandated by regulatory agencies, and changes in infection control policies and procedures.

Educate patients, family members, and caregivers regarding general infection control practices to prevent the spread of infection in the home setting.

Evaluate infection control practices when conducting supervisory home visits and identifying opportunities for improvement.

Implement appropriate action, based upon the analysis of data gathered, and evaluate the effectiveness of the designated action on an ongoing basis.

**SCOPE of MONITORING ACTIVITIES**

**A. Infection Surveillance:**

Based upon this population, as well as the increased risk of infection, total surveillance is conducted on an ongoing basis to identify areas for improvement. The surveillance indicators include, but are not limited to:

- Vancomycin Resistant Enterococcus (VRE)
- Methicillin Resistant Staphylococcus Aureus (MRSA)
- Glycopeptide Intermediate Staphylococcus Aureus (GISA)
- C. difficile associated diarrhea
- All health care associated infections
- Clusters and outbreaks of infection

**Note:** Surveillance activities in home care shall not include identification and measurement of community acquired infections. Included are upper and lower respiratory infections (e.g. colds, flu, pneumonia) gastrointestinal infections (e.g. nausea, vomiting, diarrhea and viral gastroenteritis), and other common illnesses that occur as a result of exposure to the community.

**Data collection methods include concurrent and retrospective review to include:**

- Review of 100% of the Intake sheets for infectious diseases, readmission due to possible health care associated infection and potential reportable diseases
- Review of 100% of microbiology reports to identify health care associated infection or clusters of infection
- Review of 100% of Infection Identification Patient Reports Physician diagnosed infections
- Clinical evidence such as temperature and subjective data from patient information obtained from medical records
- Information provided by staff members
- Review of telephone orders prior to data entry to identify newly prescribed antibiotics

**Definition of Home Care Acquired Infection and Analysis of Infections**

- Evidence that the infection was not present or incubating at the time of admission should be established.
- Symptoms or abnormal findings occurring greater than 48 to 72 hours after admission should prompt further investigation. There are exceptions to this and incubation periods must be taken into consideration to avoid counting infections that originated at other sites of care, i.e. chicken pox, surgical wound infection.

Compassionate Care Hospice shall follow the Center for Disease Control and Prevention's National Healthcare Safety Network (NHSN) definitions in regards to Bacteremias and Urinary Tract Infections. The Home Health Definitions shall be utilized to determine other infections. Care must be taken to distinguish between infection and colonization and community acquired infection. Definitions follow this plan.

Analysis

The numerator is the number of health care associated infections for a particular site. The denominator is the number of patients at risk for that infection or the number of days at risk (e.g., total number of catheter days for all patients with indwelling urinary catheters during the surveillance period).

Denominators for infection by site:

Catheter-associated UTI.....Total number of catheter days for all patients with indwelling Foley catheters

IV related bloodstream infection.....Total number of catheter days for all patients with venous access devices

#### **B. Additional Monitoring Indicators:**

- Monitor suspect and confirmed tuberculosis cases to ensure compliance with the TB Control Plan
- Monitor and evaluate infection control practices through chart review and home visits
- Monitor employee exposures and compliance with the Exposure Control Plan and evaluate findings to identify opportunities for improvement. These may include safer sharps safety devices, additional personal protective equipment, changes in work practices, etc.

#### **C. Policy Review**

- Review Infection Control policies and procedures annually and revise as needed. Revised policies will be submitted to the Infection Control Committee for review and approval.
- Develop new Infection Control policies as identified by the policy needs assessment. New policies and procedures are submitted to the Infection Control Committee for review and approval.
- New and revised Infection Control policies will be presented to staff at staff meetings by the Program Director or her designee.
- The TB Exposure Control Plan will be reviewed annually and revised, when indicated. A TB risk assessment will be performed annually for each office.
- The Exposure Control Plan will be reviewed annually and revised, when indicated. The annual review will include evaluation of exposure incidents. Available medical devices will be considered to reduce the risk of needlestick and sharps injuries. Exposure incidents related to work practices and personal protective equipment will be evaluated to identify the need a) for education, b) to change or alter work practices and c) to evaluate the adequacy of personal protective equipment. The plan will be revised to include the most recent guidelines from the Center for Disease Control and

Prevention on vaccinations against Hepatitis B virus and post exposure evaluation and follow up for HIV and Hepatitis C exposures.

#### **D. Employee Health**

Employee Health is an integral part of the infection control program. The Program Director is responsible for data collection, assessment, evaluation, reporting and follow-up on employees for the following:

- TB reactor data
- Needlestick and sharps injuries data and analysis
- Significant exposures data and analysis
- Epidemiological links among health care workers
- Work restrictions related to communicable diseases
- Communicable diseases exposure contact follow up

The Program Director will forward information and reports to the Coordinator of Performance Improvement (PI). The Coordinator of PI will present findings to the PIC and Infection Control Committee.

#### **E. Education**

- Education regarding infection control and prevention and policies is accomplished through formal and informal inservices.
- An inservice on Bloodborne Pathogens and the TB Control Plan shall be presented to all new orientees and, at least annually, to all other healthcare workers.
- A basic infection control and prevention inservice shall be presented annually.
- Special educational sessions will be conducted based upon need and request.
- An annual educational needs assessment will be conducted to determine programs of interest to staff members.
- Written education regarding infection prevention and control will be provided for all patients, family members and caregivers upon admission to service.

### **IV. PROGRAM IMPLEMENTATION**

Under the direction of the Infection Control Chairman, the Clinical Director is responsible for assisting staff in data collection for surveillance, educational programs, policy development and revision, compliance with local state and federal regulations, employee health and other process improvement measures to ensure quality patient care and minimize transmission of infection. The Clinical Director will ensure that there is

periodic monitoring of employee compliance with infection control practices and procedures.

The Performance Improvement Coordinator is responsible for collection of surveillance data and verification of information submitted by staff members. Surveillance reports will be written and analyzed by the PI Coordinator. Reports will be presented at quarterly PIC meetings and annually at Infection Control Committee meetings. Data will be reviewed with the Professional Advisory Committee. Evidence of clusters of infections, infections related to a specific procedure or other significant findings will be reviewed immediately with the Chairman of Infection Control committee and the Clinical Director.

Formulation and execution of the Performance Improvement Plan (PIP) for Surveillance Prevention and Control of Infection is the responsibility of the Infection Control Committee, under the leadership of the Chairperson and Clinical Director and the Performance Improvement Coordinator. The Infection Control Committee is multidisciplinary and meets at least annually to guide and evaluate the program. Additional committee meetings will be held when indicated.

Outcomes of the data collection and analysis are presented to the Performance Improvement Committee and the Infection Control Committee with feedback to the appropriate team. The Clinical Director will present findings to staff members at team/staff meetings.

There is communication of infection control data throughout the organization and between facilities when necessary. Infections that are identified, that may have been acquired while in another facility, will be reported back to that facility by the Performance Improvement Coordinator

The infection control consultant will attend Infection Control Committee meetings, act as a resource to the organization and will be available as required for consultation by telephone.

The infection control and prevention program is directed by the recommendations and approvals of the Infection Control Committee, the Centers for Disease Control and Prevention guidelines, the local, state and federal regulations, CHAP standards and current literature.

## **VI. CONFIDENTIALITY OF INFORMATION**

Data generated through Performance Improvement activities through the Hospice is considered confidential. Performance Improvement data will be released only to authorized persons employed by or affiliated with the Hospice and the agencies and institutions authorized by Administration

## **VII. APPRAISAL/EVALUATION of the PERFORMANCE IMPROVEMENT PROGRAM**

The Infection Control Committee, with assistance from the Performance Improvement Coordinator and the Clinical Director, evaluates the effectiveness of the Infection Control Performance Plan annually and as necessary.

The basis for evaluation includes:

- A. A summary of relevant findings, actions required to improve the coordination or integration of activities within the program and evidence of the program's impact on reducing the incidence of infection and improving the quality of patient care.
- B. Identification of components of the program that need to be instituted, altered, or deleted. Recommendations should assure that the program is ongoing, comprehensive, and effective in improving infection control practices and reducing infection rates.

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The Association for Professionals in Infection Control and Epidemiology (2005). APIC Text of Infection Control and Epidemiology, Volume 1, sections 1, 2, 3, 9, and 52.

Centers for Medicare and Medicaid Services; Final Medicare Hospice Conditions of Participation 2008 (418.60: Infection Control)

Original Date of PIP: 5/00

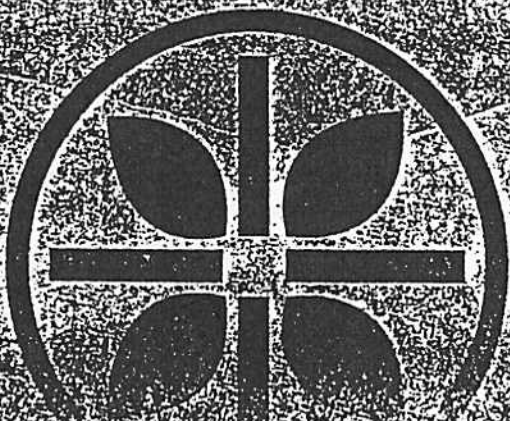
Revised: 2001, 2008

Reviewed: 2002, 2003, 2004, 2005, 2006, 2007, 2009, 2010

*"You matter  
to the last moment  
of your life..."*



*Hospice:*



*A special kind of caring*



*Most people do not want to die alone in sterile, impersonal surroundings, hooked up by tubes to machines and cut off from their family and friends and everything that's familiar.*

*Nor do they want to die in pain.*

*They would prefer, if possible, to spend their last days at home... alert and free of pain... among the people and things they love.*

*HOSPICE is dedicated to making this possible.*

*"Calling hospice is not 'giving up'... it is the opposite. For [our infant daughter], it meant a high quality of life and care from loving, committed and thoughtful professionals. For that, we are ever grateful."*

*A surviving mother*

*In our great-grandparents' time, birth and death were commonplace in the family home and accepted as natural events.*

With time and the advance of medicine, birth and death were transplanted to a new and often strange and intimidating environment: the modern hospital, where family members were merely guests and control rested with unknown health professionals.

While acknowledging the many benefits of modern medicine, a group of clergy, healthcare workers and other thoughtful people began wondering in the 1970s whether these advances, by depriving the natural dying process of its family ties, hadn't also robbed it of its dignity. Out of their concerns hospice care was born in the United States, and the natural process of dying was returned to the home.

Hospice has experienced extraordinary growth since then, with nearly 2,500 hospices now serving people in every state of the union and the District of Columbia.

Bringing death out into the open and making sickness and loss a time of sharing and remembrance is difficult. And while the hospice experience may not be for everyone, those who choose hospice find the specialness of caring for a loved one and the richness of sharing memories of youth, trials and joys a rewarding experience never to be forgotten.

Dame Cicely Saunders (founder of the first modern hospice, in London in 1968) summed up the hospice philosophy best when she told her patients:

*"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."*

# What Is Hospice?

A special kind of care for dying people, their families and their caregivers that:

treats the physical needs of patients *and* their emotional and spiritual needs,

takes place in the patient's home, or in a home-like setting,

concentrates on making patients as free of pain and as comfortable as they want to be so they can make the most of the time that remains to them,

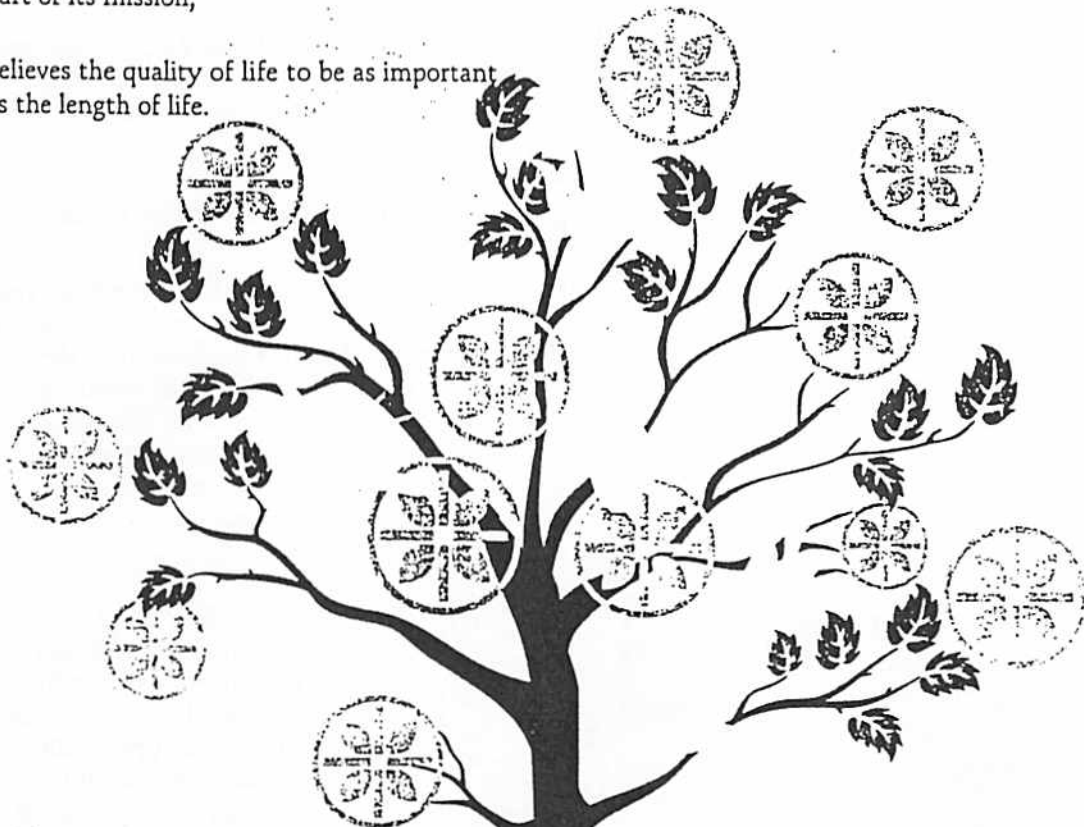
considers helping family members an essential part of its mission,

believes the quality of life to be as important as the length of life.

More than a million patients and their families have utilized the services of hospice (pronounced "HOS-pis").

Some 78 percent of all hospice patients have cancer, and many of the rest have either heart disease or AIDS. However, regardless of a patient's condition—or age—hospices open their doors and their hearts to *all* terminally ill persons.

Many surviving family members say, "I do not know what I would have done without hospice." And many credit it with helping to make their final days with their loved ones warm and memorable.



*No job is too big or too small for the hospice team—it helps in every way it can.*

This may include:

- ☛ Pain relief through medication
- ☛ Back rubs and foot massages
- ☛ Matters of personal cleanliness and coordination of necessary medical equipment
- ☛ "Being there"—to let the patient know he or she is not alone
- ☛ Talking openly about feelings

- ☛ Assisting with household chores and helping to put financial matters in order
- ☛ Providing favorite foods or music
- ☛ Joining in favorite pastimes

Though hospice professionals and volunteers are there to help, they encourage patients to be as active and to do as much for themselves as possible.

# 20 Commonly Asked Questions

Here are some of the questions most often asked about hospice. We hope they will help you better understand the hospice concept. Because individual hospices can differ, we urge you to contact your local hospice provider to find out about the program in your area.

**1** *When should a decision about entering a hospice program be made—and who should make it?*

At any time during a life-limiting illness, it's appropriate to discuss all of a patient's care options, including hospice. By law the decision belongs to the patient. Understandably, most people are uncomfortable with the idea of stopping an all-out effort to "beat" their disease. Hospice staff members are highly sensitive to these concerns and are always available to discuss them with the patient, family and physician.

**2** *Should I wait for our physician to raise the possibility of hospice, or should I raise it first?*

The patient and family should feel free to discuss hospice care at any time with their physician, other healthcare professionals, clergy or friends.

**3** *What if our physician doesn't know about hospice?*

Most physicians know about hospice. If your physician wants more information, it is available from the American Academy of Hospice and Palliative Medicine, medical societies, state hospice organizations, local hospices, or the National Hospice Helpline, 1-800-658-8898.

In addition, physicians and all others can also obtain information on hospice from the American Cancer Society, the American Association of Retired Persons, and the Social Security Administration.

**4** *Can a hospice patient who shows signs of recovery be returned to regular medical treatment?*

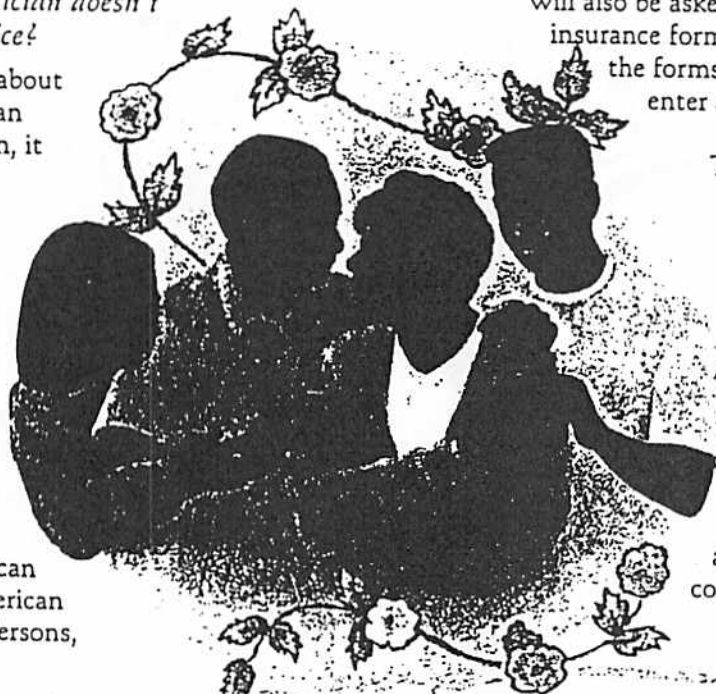
Certainly. If improvement in the condition occurs and the disease seems to be in remission, the patient can be discharged from hospice and return to aggressive therapy or go on about his or her daily life.

If a discharged patient should later need to return to hospice care, Medicare and most private insurance will allow additional coverage for this purpose.

**5** *What does the hospice admission process involve?*

One of the first things hospice will do is contact the patient's physician to make sure he or she agrees that hospice care is appropriate for this patient at this time. (Hospices may have medical staff available to help patients who have no physician.) The patient will also be asked to sign consent and insurance forms. These are similar to the forms patients sign when they enter a hospital.

The so-called "hospice election form" says that the patient understands that the care is palliative (that is, aimed at pain relief and symptom control) rather than curative. It also outlines the services available. The form Medicare patients sign also tells how electing the Medicare hospice benefit affects other Medicare coverage for a terminal illness.



**6** *Is there any special equipment or changes I have to make in my home before hospice care begins?*

Your hospice provider will assess your needs, recommend any necessary equipment, and help make arrangements to obtain it. Often the need for equipment is minimal at first and increases as the disease progresses.

In general, hospice will assist in any way it can to make home care as convenient, clean and safe as possible.

**7** *How many family members or friends does it take to care for a patient at home?*

There's no set number. One of the first things a hospice team will do is prepare an individualized care plan that will, among other things, address the amount of caregiving a patient needs. Hospice staff visit regularly and are always accessible to answer questions and provide support.

**8** *Must someone be with the patient at all times?*

In the early weeks of care, it's usually not necessary for someone to be with the patient all the time. Later, however, since one of the most common fears of patients is the fear of dying alone, hospice generally recommends someone be there continuously.

While family and friends must be relied on to give most of the care, hospices do provide volunteers to assist with errands and to provide a break and time away for major caregivers.

**9** *How difficult is caring for a dying loved one at home?*

It's never easy and sometimes can be quite hard. At the end of a long, progressive illness, nights especially can be very long, lonely and scary. So, hospices have staff available around the clock to consult with the family and to make night visits as appropriate.

**10** *What specific assistance does hospice provide home-based patients?*

Hospice patients are cared for by a team of doctors, nurses, social workers, counselors, home health aides, clergy, therapists, and volunteers—and each provides assistance based on his or her area of expertise. In addition, hospices help provide medications, supplies, equipment, hospital services, and additional helpers in the home, as appropriate.

**11** *Does hospice do anything to make death come sooner?*

Hospices do nothing either to speed up or to slow down the dying process. Just as doctors and midwives lend support and expertise during the time of child birth, so hospice provides its presence and specialized knowledge during the dying process.

**12** *Is the home the only place hospice care can be delivered?*

No. Although most hospice services are delivered in a personal residence, some patients live in nursing homes or hospice centers.

**13** *How does hospice "manage pain"?*

Hospice nurses and doctors are up-to-date on the latest medications and devices for pain and symptom relief. In addition, physical and occupational therapists assist patients to be as mobile and self-sufficient as possible, and they are often joined by specialists schooled in music therapy, art therapy, diet counseling, and other therapies.

Hospice believes that emotional and spiritual pain are just as real and in need of attention as physical pain, so it addresses these, as well. Counselors, including clergy, are available to assist family members as well as patients.

*"We were in great need of the extra support hospice gave us at a very critical time."*

*A surviving wife*

## 14 *What is hospice's success rate in battling pain?*

Very high. Using some combination of medications, counseling and therapies, most patients can attain a level of comfort that is acceptable to them.

## 15 *Will medications prevent the patient from being able to talk or know what's happening?*

Usually not. It is the goal of hospice to help patients be as comfortable and alert as they desire. By constantly consulting with the patient, hospices have been very successful in reaching this goal.

## 16 *Is hospice affiliated with any religious organization?*

Hospice care is not an off-shoot of any religion. While some religious organizations have started hospices (sometimes in connection with their hospitals), these hospices serve a broad community and do not require patients to adhere to any particular set of beliefs.

## 17 *Is hospice care covered by insurance?*

Hospice coverage is widely available. It is provided by Medicare nationwide, by Medicaid in some 38 states, and by most private health insurance policies. To be sure of coverage, families should, of course, check with their employer or health insurance provider.

## 18 *If the patient is not covered by Medicare or any other health insurance, will hospice still provide care?*


The first thing hospice will do is assist families in finding out whether the patient is eligible for any coverage they may not be aware of. Barring this, most hospices will provide care for those who cannot pay, using money raised from the community or from memorial or foundation gifts.

## 19 *Does hospice provide any help to the family after the patient dies?*

Hospice provides continuing contact and support for family and friends for at least a year following the death of a loved one. Most hospices also sponsor bereavement and support groups for anyone in the community who has experienced the death of a family member, a friend, or a loved one.

## 20 *If the patient is eligible for Medicare, will there be any additional expenses to be paid?*

Medicare covers all services and supplies related to the terminal illness for the hospice patient. In some hospices, the patient may be required to pay a 5% or \$5 "co-payment" on medication and a 5% co-payment for respite care. You should find out about any co-payment when choosing a hospice.



**About the hospice logo...**  
At its center, the hospice logo features a shining white light, symbolic of hope, life and love. Its outer circle represents the continuum of life, and the four lotus petals represent the physical, psychological, social and spiritual components of hospice care.



# What Does Medicare Cover?

When a Medicare-eligible patient receives services from a Medicare-approved hospice, Medicare pays almost the entire cost.

In general, coverage includes:

- ☛ Physician services
- ☛ Nursing care
- ☛ Medical appliances and supplies as appropriate
- ☛ Drugs for symptom management and pain relief
- ☛ Short-term inpatient and respite care
- ☛ Homemaker services and home health aid
- ☛ Physical and other therapies
- ☛ Counseling

## The Time To Learn About Hospice Is Before Illness Strikes

Experts agree that the time to learn about hospice is before a life-threatening illness occurs. This greatly reduces stress, should the time come when hospice services may be needed. Moreover, the earlier hospice is involved, the more it can make the patient's final days, weeks and months as comfortable and satisfying as possible.

Ideally, everyone would make their views about end-of-life care known to their families long before any illness strikes. They should also take a few simple steps to ensure that their wishes are followed if and when a crisis does occur. This involves drawing up:

a *living will* of written instructions to make known what you want done if, for example, you are seriously ill and the only way you can be kept alive is by artificial means; and

a *durable power of attorney*, which authorizes a person of your choosing (usually a spouse or close relative) to make decisions for you if you become unable to do so for yourself.

Because every state has different laws, you may wish to consult a lawyer about these documents. In them, you may want to indicate that if you ever become terminally ill, your preference is to receive hospice care.

You may also wish to contact Choice in Dying in New York City to obtain state-specific forms free of charge, or they may be obtained from your state Attorney General's office.



*"Hospice was like a blessing to me. Without their help, I would not have been able to care for my husband at home."*

*A surviving wife*

*"Words can't express how much the hospice program has helped our family cope with Mom's illness and her death. We appreciate the program so much."*

*A family member*

*"Too many people don't know about the wonderful work hospice does, not for money but out of the goodness of their hearts."*

*A 77-year-old hospice patient*

*"When I get sick, upset and need help, they are always there for me. I can call them at 3 a.m. and talk to someone."*

*A 63-year-old hospice patient*



## *Volunteers: The Heart Of Hospice*

Volunteers play an extremely important role in hospice nationwide. Without them, in fact, most hospices would not be able to carry on their work.

Of the 115,000 persons involved in hospice care in America, some 95,000 are volunteers and each year they give more than 5 million hours to helping dying persons and their families.

They provide assistance at all levels of skill. Many are relatives and friends of former hospice patients who, having seen how much hospice can help, want to contribute to its good work. To qualify to assist in patient care, volunteers must undergo a rigorous training program.

Your local hospice would be happy to have you call or visit to find out more about hospice volunteer work.

To learn about hospice in your community, check your local telephone directory. Or you can contact the NHO National Hospice Helpline at:

**1-800-658-8898.**

The National Hospice Organization  
1901 North Moore Street  
Suite 901  
Arlington, VA 22209

Visit our Website address: <http://www.nho.org>

