

## **SECTION 1: WHAT IS HOSPICE?**

Hospice is a program of care and supportive services designed to help terminally ill persons live as comfortably and as fully as possible during the last stage of their life. The Hospice organization focuses on the maximum comfort and care of the terminally ill and provides support through an interdisciplinary team of doctors, nurses, social workers, clergy and volunteers.

Hospice believes that caring for the terminally ill can be done in the home or nursing home with the family (or in conjunction with nursing home staff) as the primary caregivers. Hospice can help the family meet the physical and emotional demands of caring for their loved, as well as help ensure that the home environment is positive and stable for the patient and family.

Hospice professionals help the patient to manage pain and symptoms of their illness. Volunteers, clergy and other staff members help the patient and family prepare for and adjust to the inevitable final stage of life.

Hospice of Chesterfield County is a community-based, non-profit organization established by caring community residents. The agency is governed by a local board of directors and has served over 1,000 Chesterfield and Marlboro County residents and their families since 1993.

### **HOSPICE AND HOPE**

Does a person have to choose between hospice care and hope? Fortunately, this choice is not necessary. Instead, Hospice recognizes the importance of hope as a powerful, ever-changing force that continues through the time of living and process of dying. All patients maintain some type of hope, because hope is related not so much to an optimistic expectation of the future as to a meaningful experience of the present. Our hope is intertwined with our spirituality, our loves, beliefs and disbeliefs.

The hopes of Hospice are:

- comfort when cure is no longer possible
- personal dignity and patient control are maintained
- freedom from physical pain
- support of families

Patients may hope for:

- inner strength
- living to finish a project or attend a family event

- finding meaning in a life lived
- mending relationships
- a peaceful death
- life after death

Hope is a quality of being and the Hospice staff and volunteers strive to support the patient and family in defining, achieving and sharing their hopes.

## **Questions and Answers**

### **When should a decision about hospice care be made?**

It is appropriate to discuss all of patient's options for care, including hospice, when faced with a terminal illness. The patient and family should feel free to discuss hospice care with their physician, the hospice patient care coordinator, other healthcare providers or clergy. Patients have the right to choose hospice care. Hospice continues to treat you, but our treatment plan is based on symptom control, not curing the disease.

### **Are patients ever discharged from hospice?**

Yes. If the patient's condition improves and they no longer meet hospice criteria, the patient will be discharged from hospice. The discharged patient can re-enter the program at a later time, if needed. Patients may also stop hospice services if they wish to seek aggressive treatment.

### **How is hospice paid for?**

Medicare, Medicaid and most private insurance companies cover hospice care. However, care will not be diminished or denied due to the inability to pay.

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

No. Hospice does nothing to hasten the end of life. Our goal is comfort and support. Hospice allows death to occur naturally while being there to provide support and knowledge during the dying process.

### **Does someone need to be with the patient all the time?**

If the patient is able to get up and care for their activities of daily living, it will not be necessary to have someone with them all the time. However, if the patient is bedridden, hospice recommends someone staying with the patient all the time.

### **What if I can no longer manage my loved one at home?**

The hospice team is there to support you. You must let us know your concerns and if you feel you are unable to manage at home, the hospice team will work with you on long-term placement.

**Can the patient return to the hospital?**

Most symptoms and many procedures that are done in the hospital can be managed at home. However, a hospice nurse is available to assess your situation, discuss it with you and your physician and make arrangements for hospitalization. Patients may be hospitalized for symptom control or caregiver respite care.

**Can I still go see my doctor?**

Yes. Please let your hospice nurse know if you have any doctor appointments.

**Do I have to have a “Do Not Resuscitate” (DNR) order to be on hospice?**

No, you do not have to have a DNR order. You have the right to choose the type of care you wish to receive. You should discuss DNR status with your physician. Information concerning advance directives and DNR can be found in Section 7 of this guide.

---

**Mission Statement**

*The mission of Hospice of Chesterfield County is to provide quality, compassionate health care and support services for eligible terminally ill persons and their families, enabling them to experience death with grace and dignity.*

---

Hospice of Chesterfield County does not discriminate on the basis of race, color, national origin, religion, age, sex, mental or physical handicaps or the ability to pay for services.

## **SECTION 2: HOSPICE SERVICES**

### **The Admission Process**

Hospice of Chesterfield County serves residents in Chesterfield and Marlboro counties. Family, friends, physicians or other healthcare agencies can make referrals. All referrals will be evaluated for appropriateness of admission to hospice. Diagnoses include but are not limited to: Alzheimer's disease, dementia, ALS, stroke, end-stage AIDS, failure to thrive, cancer, and end-stage lung, cardiac or renal disease.

Admission to hospice is based upon your needs and the recommendation of your physician. Patients eligible for hospice care should meet the following criteria:

- (1) The patient or their primary caregiver must be a resident of Chesterfield and Marlboro counties.
- (2) The patient shall have a limited life expectancy with the anticipated prognosis determined by the physician to be six months or less.
- (3) The patient and the family must want hospice services and have a commitment to caring for the patient at home or shall have a designated place of residence that is willing to work with the hospice team.
- (4) It is desirable that the patient has a responsible person in the home who is willing to act as their primary caregiver or agrees to develop an alternate plan of care consistent with the patient's safety and needs and in compliance with Hospice standards of care.
- (5) The patient shall be receiving or desires palliative rather than curative treatment or care, with palliative being defined as care which enhances comfort and improves the quality of a patient's life.

On admission, the patient care coordinator will visit you and your family to discuss hospice services, assess your needs and initiate your plan of care.

### **Hours of Operation**

Hospice of Chesterfield County offices are located at 700 West Blvd. in Chesterfield and 160 Second St. in Cheraw. Our office hours are Monday through Friday, 9 AM – 5 PM (Cheraw hours are 10 AM -5 PM, except Wednesday 10 AM – 1 PM). Coverage is available 24 hours a day, 7 days a week through an emergency on-call system after our office is closed, weekends and holidays. A qualified hospice nurse is available to accept patient calls, referrals, and to arrange for patient services as needed.

## **Scope of Services**

Hospice of Chesterfield provides four levels of care appropriate to the needs of the hospice patient:

- routine home care in the patient's own home or the facility in which he or she resides;
- continuous care when a hospice patient is experiencing an acute crisis in order to help the patient remain in his or her own residence rather than be admitted to a hospital;
- inpatient respite care in a contracted facility when necessary to provide respite to overwhelmed or otherwise unable caregivers; and,
- general inpatient acute care in a contracted facility for the management of pain or symptoms that can not be managed in the patient's home.

Hospice patients and their families receive the services of hospice's interdisciplinary group which include:

- nursing services;
- medical social services;
- physician services (from the Hospice Medical Director and/or the patient's attending physician);
- counseling services (including spiritual counseling, dietary counseling and bereavement care);
- home health aide services;
- volunteer services; and,
- other therapies including physical therapy, occupational therapy, and speech-language pathology services, as identified in the patient's plan of care.

In addition to the services of the interdisciplinary group, hospice provides medical supplies and equipment and drugs that are used for the management of pain and symptom control related to the patient's terminal illness.

The scope and frequency of services provided by hospice are in accordance with the patient's needs as identified in his or her plan of care.

## **Plan of Care**

On admission, the hospice interdisciplinary team will develop an individual plan of care for you. It is based on your admission information, physical assessment, your physician's specific medication and treatment orders, and your personal wishes.

The plan includes four basic areas:

- Physical Care
- Personal Care and Comfort
- Spiritual Needs
- Psychosocial Needs and Bereavement Care

The plan is reviewed and updated based on your changing needs. Medical information will be provided to assist you in participating in your plan of care.

### **Discharge and Transfer**

A discharge or transfer from hospice may occur in the following situations:

- The level of care you need changes;
- You move out of our service area;
- You decide to seek aggressive, curative care; or,
- You no longer desire hospice care.

In the above situations, you will be given advance notice of transfer to another agency or of discharge. If you are transferred to another agency, we will provide necessary information for your continued care. In case of discharge, an assessment will be done and instructions provided for ongoing care.

### **SECTION 3: FINANCIAL INFORMATION**

Many health insurance companies offer a comprehensive hospice care benefit plan. If the patient has Medicare or Medicaid, they may become eligible for the special hospice benefit. However, care will not be denied or diminished because of an inability to pay.

Charitable donations allow Hospice to provide services to patients without a payment source. Donations are received through memorials, honorariums, individual gifts, endowments, bequests, and donations by churches, businesses and community organizations such as the United Way.

Also, Hospice of Chesterfield County operates The Sunshine Shoppe Thrift Store with funds raised being utilized to help the patients we serve. The thrift store is located at 122 Main St. in Chesterfield and is open Monday – Friday 10 AM – 5:30 PM and Saturday 10 AM – 2 PM. The phone number is (843) 623-3938. Donations of new and gently used items are greatly appreciated. Hospice also operates The Sunshine Gift Shoppe inside the Hospice of Chesterfield County office at 160 Second St. in Cheraw. The gift shop is open Monday-Friday 10 AM – 5 PM (except Wednesday 10 AM – 1 PM). The phone number is (843) 537-2008.

All donations to Hospice of Chesterfield County are fully tax deductible.

## **SECTION 4: HOSPICE MEDICARE/MEDICAID BENEFITS**

### **Covered Services**

Services provided by the hospice team will be in accordance with the physician's plan of treatment and may include:

- Scheduled home visits from registered nurses, social workers, home health aides, chaplains and volunteers.
- Scheduled visits and/or consultation by dietary, physical, occupational and speech therapy.
- Education about managing patient care needs, medications and treatments.
- Counseling and emotional support.
- Trained volunteers to assist the patient, family and hospice team.
- Durable medical equipment and supplies approved for the patient's care.
- Twenty-four (24) hour on-call service by registered nurses to answer questions and respond in a time of crisis. Other disciplines available twenty-four (24) hours per day as needed.
- Medicine to control the symptoms of the terminal illness such as pain control.
- Bereavement support is available to families throughout the year following the patient's death.

### **Durable Medical Equipment**

Hospice will arrange for necessary medical equipment needed to keep the patient at home.

The following is a list of DME covered:

- semi-electric hospital bed
- standard wheelchair
- bed side commode
- shower chair
- quad cane
- nebulizer
- oxygen and oxygen supplies
- suction equipment and supplies

The following will be considered with demonstrated medical necessity:

- overbed trapeze
- geomat

- overbed table
- IV infusion supplies
- specialty mattress
- hoyer lifts

The following is not covered:

- electric wheelchair
- lift chairs
- shower bars

Hospice of Chesterfield County has contracts with many area DME companies.

### **Pharmacy Supplies**

Symptom-control drugs related to the patient's terminal illness and necessary to keep the patient comfortable will be covered under your benefit. Through Hospice of Chesterfield County's contractual arrangement with HospiScript, patients may obtain their prescription drugs from most local pharmacies.

### **Inpatient Care**

- Inpatient services may be provided when the physician, the Hospice Medical Director and Hospice team assess the need for round-the-clock care for intensive symptom control. The goal of inpatient services is to help the patient and family become physically and emotionally stable enough to return home, when possible.
- Hospice does not provide for long term hospitalization, custodial or nursing home care.
- Inpatient care may be provided only in a hospital under contract with Hospice. Costs associated with an inpatient stay at a non-contracting hospital will be the responsibility of the patient/family and is not covered by Hospice.

### **Respite Care**

Respite Care is short-term inpatient stay which may be necessary in order to give temporary relief to those helping with a terminally ill patient's care. Respite care may be provided at the following contracting facility for up to five days at a time:

- Chesterfield General Hospital, Cheraw

## **Inpatient and Outpatient Care**

Outpatient and emergency services are available at contracting facilities when arranged by Hospice. The following is a list of facilities to be used for inpatient or outpatient care, for patients who elect the Medicare or Medicaid benefit:

- Carolina Pines Regional Medical Center, Hartsville
- Chesterfield General Hospital, Cheraw
- Marlboro Park Hospital, Bennettsville
- McLeod Regional Medical Center, Florence
- Union Regional Medical Center, Monroe, NC

## **Hospice in the Nursing Home**

Hospice is available for the terminally ill nursing home patient. Hospice has contracts with the following long-term care facilities:

- Cheraw Health Care, Cheraw
- Chesterfield Convalescent Center, Cheraw
- Dundee Manor, Bennettsville

## **What does all this mean for the patient?**

Hospice will provide or make arrangements for all:

- skilled nursing services
- medical social services
- home health aide/homemaker services
- medical supplies/equipment
- symptom control medications
- outpatient services, including laboratory testing
- additional services if needed, such as physical therapy, occupational therapy, dietary consults, etc.
- transportation to hospital if needed.

All inpatient, respite and outpatient care must be arranged by the Hospice nurse and attending physician. **If services are not pre-approved by Hospice the patient/family may be responsible for the bill for the services.**

## **SECTION 5: THE ROLE OF THE HOSPICE STAFF**

## **Medical Director**

The hospice medical director attends the interdisciplinary team meeting, gives guidance to the staff regarding the patient's plan of care, and is available to the patient's attending physician for consultation.

## **Primary Care Nurse**

On admission, you will be assigned a primary care nurse who will coordinate and manage your care. Our nurses have extensive training and clinical proficiency, and they treat all patients with compassion and understanding. Services provided by our nursing staff include:

- regularly scheduled visits
- 24-hour, 7 days-a-week on-call services
- coordination of care
- pain and symptom management
- skilled assessments
- training of family in patient's care

## **Social Worker**

A social worker is available to help the patient and their family deal with the emotional issues and challenges that may be faced during a terminal illness.

Services include:

- emotional support and guidance to the patient and family
- identification of community resources which may be available to help you
- assistance with financial concerns, if appropriate
- assistance with Living Wills, Health Care Power of Attorney and/or Durable Power of Attorney.

## **Home Health Aide**

We realize many of patients often encounter challenges of daily living concerns. That is where our home health aides make the difference. The home health aide is available to patients who have needs regarding daily activities such as bathing, dressing, grooming, hair care, nail care, skin care, shaving, ambulating assistance, linen changes, and homemaker service. Days of service vary dependent on patient needs.

## **Chaplain**

Hospice spiritual care is based on a high respect for the patients and caregivers' personal faith and beliefs. Our chaplains do not impose their belief system or seek to change the belief system of others. Instead, they are available to offer spiritual support to patients and their families as they face the challenges of a terminal illness. If desired by the patient/family, the hospice chaplain will work with your minister in developing a hospice spiritual plan of care.

### **Volunteers**

Volunteers play a vital role in hospice. Hospice of Chesterfield County has many devoted, compassionate volunteers residing in Chesterfield and Marlboro counties. These volunteers receive extensive training and work alongside the professional staff in providing support for the hospice program. They give their time to assist at a variety of levels, such as visiting patients, running errands, bereavement care, and office support. Our volunteers are good listeners, non-judgmental, and have a strong desire to reach out to others.

### **Bereavement Support**

Understanding, experiencing and expressing the feelings which come with grief becomes difficult at times. Hospice makes an effort to assist people to discover resources which are appropriate for their particular grief journey through our bereavement services. Services offered include:

- 13-month bereavement follow-up with hospice families
- individual and family counseling and support services as requested or needed
- bereavement support group meetings
- annual memorial service
- Camp Sunshine, a grief camp for children

## **SECTION 6: YOUR RIGHTS AND RESPONSIBILITIES**

## **Patient Rights**

All patients to whom our services are being provided have basic rights.

### **You have the right to:**

- be treated with dignity and respect
- have your property treated with respect
- be fully informed on admission of the type of care and treatment that you will receive, and be fully informed how billing and payment will be handled
- receive timely care from trained personnel
- know the names of the people giving the care and their duties
- timely delivery of safe and clean medical equipment and supplies
- know how to use equipment safely
- help plan your care to meet your needs
- decline treatment and know the risk of doing so
- expect confidentiality of all information related to your care
- be prepared if services are to be stopped or changed
- complete a legal living will to direct your wishes in advance for later medical care
- know how to make a complaint or request a change in service
- pain management – to receive appropriate assessment and management of pain you can expect the following:
  1. your reports of pain will be believed
  2. information about pain and pain relief measure
  3. a concerned staff committed to pain prevention and management
  4. health professionals who respond quickly to your report of pain
  5. effective pain management

## **Patient Responsibilities**

All patients receiving our services have certain responsibilities:

### **You have the responsibility to:**

- work together with your doctor and our agency to receive services
- provide complete and accurate information about your past medical history, present medications and other matters relating to your health
- provide requested insurance and financial information as well as meet any financial obligations as agreed to with hospice
- sign required consents and releases
- contact hospice before making a doctor's appointment
- be involved in your care by asking questions and sharing concerns

- follow instructions given for the patient's care
- provide a safe home environment in which your care can be given
- care for and safely use medical equipment as instructed (and only for the person and purpose it is intended)
- inform hospice of needs for supplies in advance, so timely delivery is made
- understand and accept the risk for any refusal of treatment
- treat the hospice staff and volunteers with respect
- respect hospice's policies which may restrict services our staff perform
- inform the hospice office of any dissatisfaction or concerns with your care
- call hospice for any changes in your physical condition, physician's prescription or insurance coverage
- call hospice with any change of address or telephone number, whether temporary or permanent
- report pain:
  1. ask your nurse what to expect regarding pain and pain management
  2. discuss pain relief options with your nurse
  3. work with your nurse to develop a pain management plan
  4. ask for pain relief when pain first begins
  5. help your nurse assess your pain
  6. tell your nurse if your pain is not relieved
  7. tell your nurse about any worries you have about taking your pain medication

### **Privacy**

You will be treated with consideration and respect. We recognize your right to dignity and privacy in treatment and in the care of your personal needs. At times an additional individual may be present during a visit for reasons of safety, education or supervision. This may include Medicare surveyors, media representatives, student interns, etc. Prior to visiting your home, we will ask for your permission. You have the right to refuse this request and this refusal will not compromise your care in any way.

### **Patient/Family Satisfaction**

The quality of care and your satisfaction with the care you receive is very important to us. A survey will be mailed to you. Please take a moment to complete and return to us. Your comments and recommendations help us to improve our services.

### **Complaints**

If there are concerns or complaints about services received from hospice, you may call or send written comments to:

Hospice of Chesterfield County, Inc.  
700 W. Blvd., PO Box 293  
Chesterfield, SC 29709  
(843) 623-9155

If these concerns/complaints are not resolved to your satisfaction, you may call the SC DHEC (Department of Health and Environmental Control) Hot Line at 1-800-922-6735. This hotline is available 24 hours a day, 7 days a week for the purpose of receiving complaints or questions about local home health agencies.

---

### **THE DYING PERSON'S BILL OF RIGHTS**

- I have the right to be treated as a living human being until I die.
- I have the right to maintain a sense of hopefulness however changing its focus may be.
- I have the right to be cared for by those who can maintain a sense of hopefulness, however changing this might be.
- I have the right to express my feelings and emotions about my approaching death in my own way.
- I have the right to participate in decisions concerning my care.
- I have the right to expect continuing medical and nursing attention even though "cure" goals must be changed to "comfort" goals.
- I have the right to not die alone.
- I have the right to be free from pain
- I have the right to have my questions answered honestly.
- I have the right not to be deceived.
- I have the right to have help from and for my family in accepting my death.
- I have the right to die in peace and dignity.
- I have the right to discuss and enlarge my religious and/or spiritual experiences, whatever these may mean to others.
- I have the right to retain my individuality and not be judged for my decisions which may be contrary to the beliefs of others.
- I have the right to expect that the sanctity of the human body will be respected after death.
- I have the right to be cared for by caring, sensitive, knowledgeable people who will attempt to understand my needs and will be able to gain some satisfaction in helping me face my death.

*(Created at a workshop on "The Terminally Ill Patient and the Helping Person," in Lansing, MI.)*

## **SECTION 7: ADVANCE DIRECTIVES**

You have the right to make all decisions about the health care you receive. If you do not want certain treatments, you have the right to tell your doctor, either orally or in writing, you do not want them. Most patients can express their wishes to their doctor, but some that are badly

injured or unconscious cannot. People need to know your wishes in case you become unable to make decisions yourself. The best way to be sure your wishes are followed is to sign an advance directive.

Our hospice complies with the Patient Self-Determination Act of 1990 which requires us to:

- provide you with written information describing your rights to make decisions about your medical care;
- document advance directives, place a copy in your medical record and inform all staff;
- comply with requirements of state law and court decisions with respect to advance directives; and,
- provide care to you regardless of whether or not you have executed an advance directive.

An **Advance Directive** is a legal document that gives specific directions for your medical care if you are unable to do so. It protects your rights. There are two types of advance directives: a living will and health care power of attorney.

A **Living Will** is a document stating that you want to be allowed to die a natural death and not be kept alive by medical treatment, heroic measures, or artificial means that will not improve your health. It only goes into effect when you are no longer able to make decisions for your self.

A **Health Care Power of Attorney** is a document in which you give another person the power to make decisions related to your health care. You should appoint a person you trust and who knows how you feel about health care.

Both of these documents can be changed or cancelled while you are still competent and able to do so. We must document in your medical record whether or not you have an advance directive. We also need a copy for our records. It is our policy to honor your advance directive and support your rights as a patient to participate in health care decisions. Please inform us if you execute or change any of these documents during the course of your care.

On June 12, 1991, South Carolina adopted a new living will form. The old form does not say anything about permanent unconsciousness and does not allow tube feeding to be withheld in most situations. If you signed a living will in South Carolina prior to June 12, 1991, it is still valid. However, you may want to review your living will and consider signing a new one.

A **Do Not Resuscitate (DNR)** is a specific order from your physician not to start cardiopulmonary resuscitation (CPR). This means no attempts would be made to try and restart your heart after it has stopped beating. Your wishes regarding this will be discussed at the time of your admission to hospice. This is a separate order from an advance directive and also needs to be documented in your medical record. You may change your wishes regarding your DNR status at any time.

Please ask your hospice nurse or social worker if you have any questions about the above, need more information or wish to complete an advance directive.

## **SECTION 8: MEDICATIONS**

### **Medication Management**

- The pharmaceutical needs of patients are managed in a manner consistent with applicable State and Federal laws and accepted standards of practice.
- The Interdisciplinary Group confers with an individual with education and training in drug management to ensure that drugs and biologicals meet each patient's needs.
- Medications are provided in a timely basis and are available 24 hours a day and seven days a week as needed.
- All medications are ordered by a licensed physician.
- A Drug Profile is maintained for every patient and includes a listing of the current medication orders for each patient and specifies whether the medication is or is not related to the patient's terminal illness.
- Hospice monitors the medications dispensed to and used by the patient.
- Medication is only administered by persons who have authority to do so under State laws and regulations.
- The RN Case Manager provides instruction to the patient/caregiver regarding the safe administration of medications including potential side effects and expected responses, and evaluates the patient/caregiver's ability to safely administer medications.
- Medication errors and adverse drug reactions receive immediate response and are documented and reviewed to ensure corrective action is taken to prevent future occurrences.
- Medications are dispensed in sufficient quantities to meet the needs of the patient and to minimize the potential for waste. Medications that are no longer needed are disposed of in accordance with accepted standards of practice.
- The RN Case Manager provides instruction to the patient/caregiver regarding the proper storage, handling and preparation of medications included in the patient's plan of care and documents the teaching provided.

### **Medication Safety Instructions**

The following principles should be followed with all the medications you are taking. This includes prescriptions and over-the-counter medications.

- Be sure your doctor(s), nurse(s) and pharmacist(s) are aware of any drug or food allergies that you may have had in the past.  
Drug Allergies: \_\_\_\_\_  
Food Allergies: \_\_\_\_\_
- Be sure all your doctor(s), nurse(s) and pharmacist(s) are aware of all medication you are using. This includes medications taken by mouth, injections, suppositories, drops, creams, ointments and patches.
- Take your medications with you (in the bottles) when you go to the doctor or health care facility.
- Take your medications only as directed. Notify the nurse if you miss a dose or have any questions about your medication schedule.
- Store your medications as directed. If they look different (for example, an odd color or odor) contact your nurse before you take the medications. Special storage instructions for medications, injectibles, nutritional supplements, inhalation gases:  
\_\_\_\_\_  
\_\_\_\_\_.
- Never use medications that have expired. Never use another person's medication.
- Read the labels on the medication bottles carefully for special directions or precautions.
- Only your doctor can order prescription refills. If you need a refill your nurse can contact your doctor for you.
- Medications prescribed for you should not be given to any other person.
- You are responsible for the safekeeping of all medications in your possession. In the event that a medication is missing, stolen or destroyed, Hospice may request additional information and documentation (e.g., a police report) in order to replace the medication.

- Medications that are no longer being used should be discarded. Ask your Hospice nurse how to properly dispose of unused medications.

### **Information on Food – Drug Interactions**

To take medicines correctly, please follow instructions from the physician, pharmacist and/or nurse.

- Some medicine must be taken when the stomach is empty, usually to keep food from interfering with the medicine.

**For example:** Penicillin, Isosorbide, Zithromax, Capoten, and Cardizem

- Some medicine must be taken with food, usually to protect the stomach from irritation by the medicine.

**For example:** Steroids, Nizoral, NSAIDs, Niacin, and Dilantin

- Some medicine can prevent normal absorption of nutrients.

**For example:** Antacids, Laxatives and Sulfa Drugs

- Some medicine can be affected by certain foods in the diet.

**For example:** Avoid fats and raw vegetables such as cabbage and okra if you are taking ant-coagulants (to “thin” blood).

If a medicine upsets your stomach, please talk to your physician, pharmacist or nurse.

Please remember that medicines can interfere with other medicines. Check with your physician, pharmacist or nurse before adding any over-the-counter medicine, herbal remedies, or diet/vitamin supplements.

## **SECTION 9: SAFETY**

**Please place this entire guide next to your phone.**

## **Electrical Safety**

- Identify frayed, broken or brittle wire insulation and get it replaced.
- Keep cords away from heat sources.
- Keep appliances away from oil or moisture.
- Avoid running electrical cords under the rugs.
- Never run cords through doorways or across walkways.
- Avoid tight knots in cords.
- Use extension cords only temporarily.
- Avoid “octopus” outlets – one outlet with several plugs being used.

## **Fire Safety**

- Smoke detectors are encouraged. They are most effective when placed outside the bedrooms and one on each floor level. Check batteries when you change your clocks for daylight savings time in the spring and fall. Please inform the hospice social worker if you do not have smoke detectors.
- Space heaters should be at least 36 inches from objects (including walls, furniture, curtains or clothing). Always turn space heaters off when away from the home or going to bed.
- Provide large, deep ashtrays for a household smoker. Put water on the butts before disposing of them in the trash. Never smoke in bed or while lying down.
- When cooking, keep pot handles turned inward to avoid handles being dumped and subsequent spills. For grease fires, put a pot lid over the flames and turn the burner off.
- Keep matches and lighters out of the reach of children.
- Unplug any appliance that smokes or smells like it is burning.
- A fire extinguisher should be available in the kitchen.
- Have a fire escape plan with two exit routes.
- Be sure all family members/caregivers are familiar with the plan.
- To evacuate a bed bound patient, place patient on a sturdy blanket and drag outside.

## **Environmental Safety**

- Night-lights are helpful for safe trips to the bathroom or kitchen at night.
- Handles are needed for going up and down stairs.
- Never leave objects on the steps.
- If area rugs or throw rugs are used, have edges secured to the floor with double backing tape.
- Keep electrical and telephone cords behind furniture or against the wall and not in traffic areas.

- Be aware of coffee tables and stools to avoid tripping over them. Keep pathways clear.
- Be sure adequate lighting is available throughout the house.

### **Bathroom Safety**

- Keep electrical equipment away from any source of water.
- Use non-skid decals or a rubber mat in tubs and showers.
- Handrails may be needed for entrance to and exit from the tub or shower.
- If medical equipment (i.e., feeding or IV pumps) gets wet, call the equipment agency promptly to get the equipment checked and/or replaced.
- Set the thermostat on the water heater below 120 degrees to prevent accidental scalding.

### **Oxygen Safety**

- Do not smoke around oxygen.
- Stay at least ten feet away from gas stoves or open flames.
- Do not use flammable products such as aerosol sprays, paint thinners or rubbing alcohol.
- Have a fire extinguisher available.
- Notify the fire department and local utility company that you have oxygen.

### **Medical Equipment/Supplies**

- Keep manufacturer's instructions near equipment.
- Clean and maintain equipment according to instructions.
- Follow electrical safety rules when using electrically powered equipment.
- Turn off equipment when not in use.
- Notify local electrical company of special needs in case of emergency.
- Have the number of the medical equipment company available so that you can notify them if problems arise with your equipment.
- Keep medical supplies in a cool/dry area.

### **Emergency Preparedness**

In the event of a power outage, hurricane, tornado, flooding, winter storm, or other disaster, the hospice team will coordinate your care according to the Emergency Preparedness Plan. If you need to be evacuated, a

hospice nurse will contact you to tell you where, when and how you will be evacuated. You will need to take your medications and supplies with you.

- The American Red Cross recommends that you keep the following emergency supplies on hand: flashlights, extra batteries, battery-powered radio, first aid supplies, bottled water, food that does not require heating, special items needed for infants, elderly or disabled family members, and an extra pair of glasses.
- Register with your local utility and telephone company if you have oxygen or electrically powered equipment in use.
- If we are unable to contact you, follow the instructions from your local disaster agency.

### **Floods**

Floods can develop over a period of days, but flash floods can occur in just a few minutes. Be aware of flood hazards, especially if you live in a low-lying area or near water.

If a flood watch is issued:

- gather emergency supplies
- be prepared to evacuate
- secure your home
- turn off utilities at the main switches if instructed to do so
- do not walk through moving water
- use a stick to check the firmness of the ground in front of you

### **Tornado**

A tornado is nature's most violent storm. They move rapidly. In case of a tornado warning:

- Stay away from windows, doors and outside walls.
- Go to an interior room of your home that does not have windows, always on the lowest level.
- If a patient is bed bound, move the bed away from the window and cover with heavy blankets.
- If you are in a car or in a mobile home, get out and go to a nearby building. If one is not available, lie flat in the nearest ditch. Cover your head with your hands.

### **Hurricane**

High winds, heavy rain, flooding and tornadoes can cause damage to your home and surroundings. Being prepared is essential. If a hurricane watch is issued:

- gather emergency supplies
- secure your home
- fill your car's gas tank
- listen to the advice of local officials
- if instructed, evacuate to a shelter (take a supply of clothing, sleeping bag, and medication with you)
- stay indoors, away from windows

### **Winter Storms**

Extreme cold, snowfall and icy conditions can cause blocked roadways, accidents and downed power lines. In case of a winter storm:

- gather emergency supplies
- dress in several layers of warm clothing rather than one layer
- always wear a hat – most body heat is lost through the top of your head

### **Guidelines for Restraint Use**

It is the philosophy of Hospice that in cooperation with our patients and their families, we will create and maintain an environment that fosters minimal use of restraints. The patient's rights, dignity, and well being are to be supported and maintained at all times.

A restraint is any method of restricting an individual's freedom of movement, physical activity or normal access to the body.

Physical restraint is any device used to physically restrict a person's freedom of movement, physical activity, or normal access to the body.

Chemical restraint is the inappropriate use of a sedating drug to manage or control behavior.

Alternatives to restraint use may include, but are not limited to:

- scheduled position changes or ambulating
- diversional activities
- pain, comfort measures
- reorientation as needed
- involvement of family/primary care giver in care
- calm, quiet environment
- use of a lounge chair
- adaptive scheduled exercises from occupational or physical therapy

Narcotics and sedatives may be used for symptom control. These drugs decrease the patient's ability to perform the activities of daily living while at the same time keeping them comfortable. Dosages are changed only under a physician's order and in amounts needed to control the patient's symptoms.

Restraint Application: Use/apply restraints according to manufacturer's instructions.

- Restraints should be applied to allow for some movement.
- Pad wrist and ankles before applying restraints.
- Release, reposition and exercise the patient **every two hours**.
- Offer nourishment and use of toilet facilities **every two hours**.
- Observe skin integrity and circulation **every hour**.
- Always secure restraints to the bed frame with a slip knot, **never** to the side rail.

Restraints are a temporary solution to a situation and will be initiated only after other alternatives have failed. Your primary RN will assess the patient to determine that appropriate less restrictive alternatives have been exhausted and to select the appropriate type of restraint based on the behavior requiring restraint. For any questions you may have regarding restraint use and alternatives, contact your primary nurse.

## **SECTION 10: INFECTION CONTROL**

Illnesses that spread from one person to another are called infectious diseases. Each one has its own way or ways of spreading. Contact with

infected body fluids (such as blood, urine, feces, and mucus) or with the droplets that are sprayed into the air when an infected person sneezes or coughs is a way an infectious disease can spread. Sometimes, the illness can spread through an indirect link, such as having contact with items that have been freshly soiled by drainage from infected sores or discharges from the patient's body openings (nose, mouth, eyes, rectum, etc.).

Controlling the spread of an infectious disease means interrupting the way the illness travels from an infected person to a non-infected person. For example, if you have a cold and cover your mouth when you sneeze, you are stopping the spread of infected droplets.

Careful personal hygiene and household cleanliness are very effective in preventing the spread of disease. These and other helpful infection control measures are discussed below.

**Maintain good personal hygiene.**

- Wash your body every day.
- Wash your hair at least weekly.
- Brush your teeth and rinse your mouth after every meal and at bedtime.
- Trim your fingernails and toenails weekly.
- Wear clean and laundered clothes.
- Change dirty clothing and bed linens as soon as you notice the soiling.

**Wash your hands frequently. This is the single most important step in controlling infection.**

- a. Wash your hands before:
  - food preparation
  - eating food
  - serving food
- b. Wash your hands after:
  - using the toilet
  - contact with your own or another's body fluids
  - blowing or wiping your nose
  - outside activities

**Wash your hands thoroughly.**

- Wet your hands with plenty of soap and warm water.
- Work up lather over your hands and wrists.
- Rub the palm of one hand over the back of the other and rub them together several times. Repeat for the other hand.
- Interlace the fingers of both your hands and rub them back and forth.
- Clean under your fingernails with a nailbrush or orange stick.

- Rinse your hands thoroughly under warm running water.
- Dry your hands and wrists thoroughly.

**Clean contaminated household and medical equipment thoroughly.**

**Gloves should be worn.**

- Scrub medical equipment with a 70% alcohol solution or a solution of one part bleach to 10 parts water.
- Clean soap dishes, denture cups, etc. weekly.
- Do not use the same sponge to clean the bathroom and kitchen.
- Do not pour mop water down the kitchen sink.
- Disinfect mops and sponges weekly by soaking in a one-part bleach to 10 parts water solution for 5 minutes.
- Flush body wastes down the toilet.
- Do not clean bedpans, potty seats, urinals, etc. in the kitchen sink.
- Do not share towels, washcloths, lingerie, undergarments, toothbrushes or razors.
- Clean up blood/body fluid/spills with 1:10 bleach solution. Gloves should be worn.
- Soiled laundry should be washed separately in hot, soapy water and a 1:10 bleach solution if a viral contaminant is present.

**Decrease your exposure to people with infectious diseases.**

- Avoid crowds whenever possible.
- Avoid people who have been recently vaccinated.
- Avoid people with bacterial infections, cold sores, shingles, influenza, colds, chicken pox, measles, etc.
- Cover your mouth with a tissue or your hand when sneezing and coughing.
- Do not share food and drink with others.
- Do not lick your fingers or taste from the mixing spoon while cooking.

**Gloves**

- Should be worn if contact with blood, urine, feces, mucous membranes, open wounds, or other body fluid.
- Wash hands before and after wearing gloves.
- Gloves are unnecessary with casual contact.
- Gloves should not be reused.
- If contact with blood/body fluids occurs, body surfaces should be immediately washed with soap and water.

**Eating, drinking, applying chap stick, or handling contact lenses in the patient care area could result in exposure.**

**Disposal Guidelines**

- You should place needles, lancets and other sharp objects in puncture resistant, closable, leak proof containers. **Do not** put

sharp objects in any container that will be recycled or returned to a store. **Do not** use glass or clear plastic containers with sharp objects. Keep all out of the reach of young children.

- Soiled bandages, medical gloves, chux, etc. should be double bagged in securely fastened plastic bags before you put them in the outside garbage with your other trash.

## **SECTION 11: PRIMARY CAREGIVER GUIDELINES**

Caring for a loved one who has a terminal illness and who is undergoing many physical, emotional, mental and spiritual changes, can be a challenging and fulfilling experience, as well as confusing and tiring. Hospice supports your willingness to undertake the role of Primary Care

Giver for your loved one. By doing so, you are allowing them to remain in comfortable and familiar surroundings during life's final journey.

Our Hospice staff realizes that this period of time is one of the most difficult times for the family to live through, sometimes because "fear of the unknown" is greater than fear of the known. Our desire is to be as honest and straight forward as possible in helping you through this period. We are here to provide information to help you prepare for and understand symptoms which may be seen toward the end of life. By working as a team, each one having different roles and responsibilities, we can provide the most benefit to you and your loved one.

**Primary care** refers to the basic physical and emotional activities involved in caring for the activities of daily living of your loved one at home. You may be asked to do such things as maintain the patient's hygiene, nourishment and give medications. It may involve such comfort measures as preventing constipation and nausea, turning, skin care, oral care, bathing, and grooming. You may be asked to learn such skills as ostomy care and how to use special equipment. Generally, it means being available to your loved one to listen, to touch, to share, to be present and to care.

Your individual Hospice team will support you in every possible way as you undertake this role. We will help you deal with your limitations and frustrations. We will help you arrange for all supportive services that are needed in the home and deal with your own feelings regarding this situation and how it is affecting your life. We will help you clarify your available options and implement them in the most helpful manner.

Your Hospice team will explain the progression of the illness, how the needs of your loved one will change, and how to respond as these changes take place. We want to describe possible symptoms to you in order to decrease your fear if one should appear suddenly, and give you some guidelines about what you can do about the symptoms. The symptoms described are indicative of how the body prepares itself for the final stage of life, but not all of these symptoms will appear at the same time and may never appear.

If you think death has occurred, please call the Hospice office. We will send a Hospice nurse to make a home visit. The nurse will handle calls to the coroner and your doctor. You will not need to call the police, paramedics, EMS or the fire department.

Please know that although this information may sound frightening, our goal is to prepare you for what to expect. Your physical and emotional well being are as important to us as the dying person's. The value of the

gift of care giving will make the patient's remaining time on earth full of meaning, dignity, and respect. In doing all you can to facilitate your loved one's comfort and peace, you are also giving yourself a great gift.

## **SECTION 12: SYMPTOM MANAGEMENT**

### **Pain Management**

Although not all hospice patients experience pain, the fear of pain and reality of pain are major concerns. It is your right as a patient to have your

pain assessed and treated. It is our goal to manage your pain thereby increasing your comfort level and improving the quality of your life. When pain is under control you can eat, sleep, and perform daily activities more normally.

Many people report less pain than they are actually having. Reasons for this vary but may include the following:

- Belief that pain and illness go hand-in-hand and that the pain must be tolerated.
- The fear that an increase in dosage means the disease is worse.
- Fear of developing a tolerance or addiction to the medication.
- Cultural or religious beliefs about pain.

Communication is the key to effective pain management. Only you can tell us about your pain and if your medications are effective. On each visit, the nurse will assess the source and type of pain you experience and ask you to rate your pain on a scale of 1 to 10. It is important that you answer honestly about the level of pain you experience and how often it occurs. With this information, the hospice nurse will be able to work with your physician to develop a pain management plan.

Patients experience different types of pain. The signs of pain may vary: some patients may moan, experience a rapid heart rate, or become restless. However, if this does not occur it does not mean the patient is not having pain. For these reasons, it is important for patients to speak openly and honestly with their nurse or doctor about pain.

Usually, pain can be controlled with medication taken orally rather than by injection. Patients remain more comfortable when they take regular doses of medication around-the-clock. These are time-released medications that keep a constant level of pain medication in your system. This prevents the patient from experiencing “peaks and valleys” of his or her pain. For those periods of time when pain “breaks through,” an immediate release medication is prescribed.

Dosages and effects are monitored and evaluated on a regular basis by the hospice nurse. If the patient has problems swallowing, pain medication in the form of rectal suppository, skin patch, or a medication under the tongue can be used.

**REMEMBER:**

- Some patients have no pain.
- Some pain medications are to be given on a regular schedule, around-the-clock. This helps to keep patients more comfortable.

- There is no reason to worry about addiction. Addiction is defined as “the compulsive use of a drug for non-medical purposes, usually with harm to the individual.” Your medication is scheduled and being monitored. Studies show that patients do not become addicted to the amount of medication needed to control pain.
- Do not be alarmed if the patient becomes drowsy or sleepy for a few days after starting a new medication or after increasing the dosage. This is not unusual; it takes time for the body to adjust to the new medication or dosage.
- Tell the hospice nurse immediately if your pain medication is not working.
- Notify the hospice nurse when your medication gets low – not when it’s gone.
- Do not stop taking your pain medication on your own.
- The use of music or other relaxation techniques may be helpful in easing pain.

## **Nutrition**

Food plays an important part in our lives. We use food to celebrate the important events like weddings and birthdays. However, many hospice patients have a decrease in appetite and thirst, wanting little or no food or fluids. The patient may be disturbed by the smell of food, may feel “too full” or just not have the energy to eat. **This is to be expected.**

There are many possible causes for this loss of appetite, such as the disease process, changes in taste or smell, difficulty swallowing, and nausea/vomiting. The hospice team will offer suggestions to the caregiver and patient that will make mealtime less stressful. The following are some general suggestions:

- Do not force patients to eat.
- Serve the meal in a relaxed, comfortable, and pleasant atmosphere.
- Give mouth care prior to the meal to freshen the mouth.
- Appetite is better at the beginning of the day and decreases as the day progresses, so make the most out of breakfast and lunch.
- Try smaller, more frequent meals or snacks.
- Use every opportunity to add calories, such as offering fruit juices or milk instead of water when giving medications.
- Giving pain or nausea medications prior to eating may be helpful.
- Soft food may be easier to eat and less tiring.
- Liquids may be given in other forms such as Jell-O, popsicles, pudding or broth.
- Patients can be kept comfortable with sips of water or ice chips rather than an IV. When the patient is dying, the need for food and fluids decreases and forcing either can cause discomfort.

If **NAUSEA** is a problem, you may try the following:

- Avoid foods that may aggravate nausea such as spicy, greasy, or fried foods.
- Serve bland foods that don't have much odor.
- Serve small meals and encourage the patient to take their time.
- Raise the head of the bed and keep elevated while eating.
- Allow the patient to rest after eating.
- Medication for nausea may be ordered to be given 30 minutes before eating.

If **DRY MOUTH** is a problem, you may try the following:

- Try sips of water, popsicles, or ice chips.
- Suck on hard candy.
- Avoid extremely hot or cold foods.
- Keep lips moist with a petroleum jelly.

**REMEMBER:**

- A loss of appetite is expected.
- It is okay if patients do not eat everyday.
- Do not force food, instead offer and encourage food and drink.
- Give positive encouragement and allow the patient to be in charge.
- Serve small, frequent meals.
- Improving food intake rarely helps improve weakness.

The following recipe may be used for patients who have a decreased food intake:

### **High Calorie/High Protein Shake**

½ cup whole milk  
ice cream to taste (½ cup)  
any fruit of choice  
½ - 1 tsp. Mazola cooking oil  
1 tbsp. Carnation Instant Milk (powdered)  
1 tbsp. malted milk

blend above together

300 calories

9 grams of protein

14.5 – 17 grams of fat (depends on amount of oil used)

### **Elimination**

Problems with elimination are often a source of concern, anxiety and discomfort for hospice patients. Bedside commodes may be used so

patients don't have as far to walk to the bathroom. If control of elimination is lost, diapers and chux may be used.

In some cases, a foley catheter may be used to drain the urine. The hospice nurse will assess each situation and discuss options with you. You will be taught how to care for and irrigate (if needed) the foley catheter.

Bowel habits are different for each patient. However, patients should have a bowel movement every 2-3 days even when food intake is low. Caregivers should keep a record of bowel movements. The hospice nurse will be assessing bowel status on each visit.

Constipation is a common problem for hospice patients. Pain medication, food/fluid intake and decreased mobility all contribute to constipation. Prevention of constipation is the best plan of treatment. This plan may include:

- increase fluid intake
- fruit juices, especially prune juice, may be helpful
- provide privacy and comfort to the patient
- upright position
- use of stool softener and laxative combination

Diarrhea may also be a problem for hospice patients. The hospice nurse will assess the situation and try to determine the cause of it. Management of diarrhea may include:

- Elimination of foods that may cause diarrhea, such as dairy products, whole grains, beans, nuts, raw fruits and vegetables.
- Drinking fluids after meals instead of with meals.
- Encouraging increased fluid intake.
- Washing the rectal area after each loose stool and apply a skin barrier such as Vaseline or A&D Ointment.
- Use of medication if recommended.

**Remember:**

- Keep a record of bowel movements.
- Notify hospice if there is no bowel movement in 3 days.
- Increase fluid intake.
- Give laxatives as ordered.

**Skin Care**

It is important to try and keep the patient's skin in good condition. Due to their disease, hospice patients may have weakness, loss of weight, and low nutritional intake, all of which can cause skin problems. Bedsores or decubitus ulcers may occur in those who are confined to bed and don't

change their position. The most likely areas to develop bedsores are the sacrum, elbows, heels and hips.

When the patient remains in a chair or bed for an extended period of time, it is important to take precautions. Some helpful steps to follow are listed below:

- Check the patient's skin each day for reddened areas or breakdown.
- Turn every 2-3 hours. This helps to relieve the pressure. With a bed-bound patient, a sheet can be used to assist with turning or lifting. The hospice home health aide or nurse will teach the caregiver how to use a draw sheet.
- Use lots of pillows to both support and comfort the patient.
- Give pain medications as scheduled to make sure that movement is as pain free as possible.
- Keep the patient's skin clean and dry.
- Keep the bed linens dry and wrinkle free.
- Gently massage reddened areas. Apply lotion to skin once or twice each day to prevent dryness.
- Eggcrates, heel and elbow protectors may be helpful.

In spite of all efforts, a bedsore may still develop. If this occurs, the hospice nurse will help determine the best way to treat the bedsore.

### **Mouth Care**

Mouth care is also important for hospice patients. Regular mouth care may prevent sores and may improve the patients desire to eat.

Tips on mouth care:

- Allow patient to perform own oral care if able.
- Perform mouth care at least 2 times a day.
- Do not perform mouth care with the patient lying flat.
- Use a moisturizer, such as Vaseline, on lips to prevent drying. Apply as needed throughout the day.
- If mouth sores develop, notify hospice.

### **Difficulty Breathing**

Sometimes breathing difficulties, known as shortness of breath, can occur in hospice patients. You may notice feelings of anxiety, restlessness, as well as faster breathing. Things you can do to help include:

- Be calm and reassuring. Stay with the patient.

- Raise the head of the bed.
- Fans and cool air humidifiers may be helpful.
- Give medication for pain or anxiety as ordered.

Please call your hospice nurse about difficulty breathing. Your physician may order oxygen.

### **Anxiety, Confusion, Restlessness**

The patient may experience changes in behavior such as anxiety, confusion, and restlessness during the disease process. Often it is hard for both the patient/family to experience. These changes are normal and to be expected. Things you can do to help:

- Respect the patient's mood.
- Maintain a consistent environment with familiar objects.
- Keep room quiet. You may need to limit visitors.
- Have a calendar and clock available to maintain orientation.
- Use a night light.
- Sit with the patient and maintain physical contact, like a light touch or hand holding.
- Verbal reassurance.
- Reading to the patient.
- Soft music.
- Medications if ordered.

Your hospice team will be available to talk with you about these changes and provide you with support. Remember that it is important for you to take care of yourself during this time by getting rest, maintaining your diet, and arranging some time just for you. Hospice wants to assist you in providing the best possible care for your loved one.

### **Fall Prevention**

Hospice patients may experience weakness, fatigue, balance problems, or changes in the way the body works which may cause the patient to fall more easily. The tips listed below may help to prevent the patient from falling. You may also find other helpful tips in the Home Safety section of this book under Environmental and Bathroom Safety.

- Have patient sit on the side of the bed for one to two minutes before trying to stand or move to a chair.
- Shoes should be low-heeled with non-slip soles; bare feet are safer than socks or soft slippers.
- To help the patient stand, place yourself in front of the patient, put your forearms under their armpits, bend your knees and using your legs (not your back) lift the patient to a standing position.

- Assist the patient to walk. If they begin to fall put your arms under their armpits and lower them gently to the floor.
- Place beds and chairs against the wall so they won't move when the patient is getting up or down.
- Lock the wheels on a wheelchair and hospital bed before assisting the patient to get up.
- Provide bright lighting throughout your home.
- Remove throw rugs or tape the edges down on larger rugs.
- Keep pathways clear of small items, telephone and electrical cords.
- Pad sharp corners on furniture by taping a small towel on the corner.
- Mop up spills on the floor if they occur.

Even by following the above prevention steps, a fall may still occur. If this does happen, please notify hospice immediately.

---

## **HOW TO LIVE WITH A LIFE-THREATENING ILLNESS**

### **WITH THE HELP OF HOSPICE YOU CAN:**

- Talk about the illness. If it is cancer, call it cancer. You can't make life normal again by trying to hide what is wrong.
- Accept death as a part of life. It is.
- Consider each day as another day of life, a gift from God to be enjoyed as fully as possible.
- Realize that life never is going to be perfect. It wasn't before, and it won't be now.
- Pray, if you wish. It isn't a sign of weakness; it is your strength.
- Learn to live with your illness instead of considering yourself dying from it. We are all dying in some manner.
- Put your friends and loved ones at ease. If you don't want pity don't ask for it.
- Make all practical arrangements for your funeral, will, etc., and make certain your family understands them.
- Set new goals; realize your limitations. Sometimes the simple things of life become the most enjoyable.
- Discuss your problem with your family, including your children, if possible. After all, your problem is not an individual one.

*(Orville Kelly in MTC Newsletter)*

## **SECTION 13: SIGNS OF APPROACHING DEATH**

### **Normal Emotional & Spiritual Signs & Symptoms of Approaching Death with Appropriate Responses**

Withdrawal: The patient may seem unresponsive, withdrawn, or may be in a comatose-like state. This indicates preparation for release, a detaching from surroundings and relationships, and a beginning of “letting go.” Since hearing remains until the end, speak to your loved one in your

normal tone of voice, identify yourself by name when you speak, hold his/her hand, and say whatever you need to say that will help the person "let go."

Vision-Like Experiences: The person may speak to or claim to have spoken to persons who have already died or to see or have seen places not presently accessible or visible to you. This does not indicate hallucination or drug reaction. The person is beginning to detach from this life and is being prepared for the transition so it will not be frightening. Do not contradict, explain away, belittle or argue about what the person claims to have seen or heard. Just because you cannot see or hear it does not mean that it is not real to your loved one. Affirm his or her experiences. They are normal and common.

Restlessness: The person may perform repetitive and restless movements. This may in part indicate that something is still unresolved or unfinished that is preventing him/her from letting go. Your hospice team members will assist you in identifying what may be happening and help you find ways to help the person find release from the tension or fear. Other things helpful in calming the person include recalling a favorite place or experience, reading something comforting, playing music and giving assurance that it is okay to let go.

Decreased Socialization: The person may only want to be with a very few or even just one person. This is a sign of preparation for release.

Giving Permission: Giving permission to let go without making your loved one feel guilty for leaving can be difficult. Trying to keep your loved one with you to meet your needs can also be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, to be sure that those who are going to be left behind will be all right. Affirm the person's ongoing value to you and the good received from him/her you will carry forward into your life. Therefore, your ability to release the dying person from this concern and give assurances that it is alright to let go whenever he/she is ready is one of the greatest gifts you have to give your loved one at this time. You may help your loved one by giving permission to let go whenever he/she is ready.

Saying Good-Bye: When the person is ready to die and you are able to let go, then is the time to say "Good-bye." Saying "Good-bye" is your final gift of love to your loved one, for it achieves closure and makes the final release possible. You may lie in bed with the person and say everything you need to say. It may be as simple as saying, "I love you." It may include recounting favorite memories, places and activities you shared. It may include saying, "I'm sorry for whatever I contributed to any tensions or difficulties in our relationship." It may also include saying, "Thank you for..." Tears are normal and a natural part of saying "Good-bye." You do

not need to hide or apologize for tears. Tears express your love and help you let go.

### **Physical Signs of Approaching Death**

The following signs and symptoms described are indicative of how the body prepares itself for the final stages of life:

Coolness: The person's hands and arms, feet and then legs may be increasingly cool to the touch, and the color of the skin may change. The under-side of the body may become darker and the skin mottled. This is a normal indication that blood circulation to the body's extremities is decreasing and being reserved for the most vital organs. Keep the person warm with a light blanket.

Sleeping: The person may spend an increasing amount of time sleeping, and may appear to be uncommunicative or unresponsive and at times be difficult to rouse. This normal change is due in part to changes in body metabolism. Sit with your loved one, holding a hand, speaking softly and naturally. Do not shake your loved one or speak loudly. Plan to spend time with him/her during those times when he/she seems most alert and aware. Speak to him or her directly, as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

Disorientation: The person may seem to be confused about the time, place, or identity of even close and familiar people. This is due in part to metabolic changes. Identify yourself by name as you enter, rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something for the patient's comfort. Say, "It is time to take your medication" and explain the reason, "so you won't begin to hurt." Do not use this method to try to manipulate the patient to meet your needs.

Incontinence: The person may lose control of urine and/or bowel matter as muscles in that area begin to relax. Discuss with your hospice nurse what can be done to protect the bed and keep your loved one clean and comfortable.

Congestion: The person may have gurgling sounds coming from the chest, as though marbles were rolling around inside. These sounds may become very loud. This normal sound is due to the decrease of the fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the person's head to the side, raise the head of the bed and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist

cloth. The sound of congestion does not indicate the onset of severe or new pain.

Restlessness: The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolic changes. Do not interfere with or try to restrain such motions. To have a calming effect, speak in a quiet, natural way; lightly massage the forehead, read aloud, or play some soothing music.

Fluid and Food Decrease: The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy expended on these functions. Do not try to force food or drink into the person. Do not try to use guilt to manipulate him/her into eating or drinking; this only makes the person much more uncomfortable. The mouth may become dry and sore and swallowing may become difficult. Cleaning the mouth with swabs may be helpful. The mouth may be lubricated by using cooking or mineral oil. If swallowing is a problem, consult your hospice nurse.

Urine Decrease: The person's urine output normally decreases and may become tea-colored (referred to as concentrated urine). This is due to the decreased fluid intake as well as the decrease in circulation through the kidneys. Consult your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

Breathing Pattern Change: The person's regular breathing pattern may change. A particular pattern of irregular breathing of 5 to 30 seconds (and up to a full minute) is called "Cheyne-Stokes" breathing. The person may also experience periods of rapid, shallow, panting-like breathing. These patterns are very common and indicate a decrease in circulation in the internal organs. Elevate the head and/or turn the person on his/her side to help ease breathing. Speak gently.

## **SECTION 14: EMERGENCY PLAN**

A registered nurse is on-call at all times. We are available for emergency situations after hours. **Please do not call 911 before calling the on-call nurse.** We will handle the situation as needed. Below we have listed reasons for contacting us after hours as well as problems that may be handled during regular hours. However, please contact us at any time with questions or concerns you may have.

## **AFTER HOURS EMERGENCY SITUATIONS**

- Falls or injuries
- Uncontrolled pain
- Trouble breathing
- Uncontrolled nausea, vomiting or diarrhea
- Seizures
- Uncontrolled bleeding
- Agitation or restlessness
- Temperature above 101 that does not respond to Tylenol
- Unable to wake patient
- Death

## **PROBLEMS THAT ARE HANDLED DURING OFFICE HOURS 9 AM – 5 PM, Monday through Friday**

- Medication refills
- Messages for hospice staff
- Ordering supplies/equipment
- Questions about the home health aide schedule
- If you will not be home when a visit is scheduled

## **EMERGENCY NUMBERS**

**Weekdays 9 AM – 5 PM**

**(843) 623-9155 or 1-800-572-9322**

**After Hours, Weekends, Holidays**

**(843) 623-3832**

The answering service will answer and take your information. A nurse will return your call.

If you have not received a call within 10 minutes, then dial

**(843) 537-7881**

The operator at Chesterfield General Hospital will answer this number. Identify yourself as a Hospice Patient/Family and tell them you have an emergency and need to talk with the Hospice Nurse "On-Call" and ask them to page her/him. Give your name, phone number, and any other information that is requested. The Hospice Nurse will be contacted and will return your call.

**DO NOT PANIC AND CALL 911 OR AN AMBULANCE. KEEP THE PHONE LINE FREE SO THE NURSE CAN GET YOU.**

**SECTION 15: YOUR HOSPICE STAFF**

PATIENT CARE COORDINATOR: \_\_\_\_\_

NURSE: \_\_\_\_\_

HOME HEALTH AIDE: \_\_\_\_\_

SOCIAL WORKER: \_\_\_\_\_

CHAPLAIN: \_\_\_\_\_

VOLUNTEER: \_\_\_\_\_

**VISIT SCHEDULE**

<b><u>Service Provided</u></b>	<b><u>Frequency</u></b>
Nurse:	_____
Home Health Aide:	_____
Social Worker:	_____
Chaplain:	_____
Volunteer:	_____

**SECTION 16: THANK YOU**

We at Hospice of Chesterfield County thank you for the privilege of assisting you with the care of your loved one. We salute you for all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calmness, and to enable your loved one to leave this world with a special sense of peace and love.

You have given your loved one the most wonderful, beautiful and sensitive gifts we humans are capable of giving. In giving that gift, you have given yourself a wonderful gift as well.