

# FAMILY PACKET

*Information for HospiceCare  
Patients and Families*

## IMPORTANT:

Call HospiceCare any time day or night if:

- You are a new patient arriving home from the hospital
- You are having an Emergency
- You have any questions, day or night

Call HospiceCare 24 HOURS A DAY at:  
(304) 768-8523 or (800) 560-8523 or (304) 342-5151



1606 Kanawha Blvd., West ❖ Charleston, WV 25312-2536  
304.768.8523, 800.560.8523, Fax: 304.768.8627  
[www.hospicecarewv.org](http://www.hospicecarewv.org)

## TABLE OF CONTENTS

- **IMPORTANT NUMBERS**
- **MY QUESTIONS**
- **BASICS ABOUT THE HOSPICE PROGRAM**
  - 4 Hospice is about Living as Fully as Possible
  - 4 Family's Role
  - 5 Services Provided with HospiceCare
  - 6 How Are Hospice Services Paid for?
  - 8 Where is Hospice Care Provided?
  - 9 More Information about the Hubbard Hospice House
  - 10 We Signed Up for Hospice in the Hospital, What Now?
  - 11 On-Call Services
  - 12 Can We Call 911?
  - 13 Frequently Asked Questions
  - 14 Patient Rights and Responsibilities
  - 14 Concerns/Complaints
  - 15 Notice of Privacy Practices
- **PATIENT CARE INFORMATION FOR HOSPICE FAMILIES**
  - 17 Pain Relief
  - 18 Other Comfort Measures
  - 19 Problems with Swallowing
  - 19 Relieving Dry Mouth
  - 20 Nutrition
  - 21 Nutritional Hints
  - 22 What Happens When He Can No Longer Eat or Drink?
  - 23 Medication Safety
  - 24 Infection Control
  - 25 Fall Safety
  - 25 Special Consideration for Confused Patients
  - 25 Fire Safety
  - 26 Disaster Safety
  - 27 The Final Days—What to Expect
  - 31 When Death Occurs
  - 32 Spiritual Care
  - 33 Living with Loss and Grief
- **WHAT AM I SUPPOSED TO DO NOW?**

## Important Numbers



[www.hospicecarewv.org](http://www.hospicecarewv.org)

*Serving families in  
these West Virginia  
counties:*

**Boone  
Braxton  
Clay  
Fayette  
Greenbrier  
Jackson  
Kanawha  
Lincoln  
Mason  
Monroe  
Nicholas  
Pocahontas  
Roane  
Summers  
Webster**

### **Main Office**

**1606 Kanawha Boulevard West, Charleston, WV 25312**  
(304) 768-8523, (800) 560-8523, Fax (304) 768-8627

### **Hubbard Hospice House**

**1001 Kennawa Drive, Charleston, WV 25311**  
(304) 926-2200, Fax (304) 926-2238

### **Lewisburg Office**

**223 Maplewood Avenue, Lewisburg, WV 24901**  
(304) 645-2700, (800) 237-0842, Fax (304) 645-3188

### **Boone Office**

**467 Main Street, Madison, WV 25130**  
(304) 369-0183, (800) 560-8523, Fax (304) 304-369-5842

### **Summersville Office**

**1129 Broad Street, Suite 300, Summersville, WV 26651**  
(304) 872-7431, (800) 523-0561, Fax (304) 872-7432

### **Other Numbers and Information:**

Pharmacy: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

# My Questions

Please feel free to list below questions you may have and want to discuss with the HospiceCare staff:

Care Needs \_\_\_\_\_

\_\_\_\_\_

Relief \_\_\_\_\_

\_\_\_\_\_

Medications \_\_\_\_\_

\_\_\_\_\_

Pain Relief \_\_\_\_\_

\_\_\_\_\_

Prayer/Communion/Services \_\_\_\_\_

\_\_\_\_\_

Fixing Relationships \_\_\_\_\_

\_\_\_\_\_

Wants and Dreams \_\_\_\_\_

\_\_\_\_\_

Financial Concerns \_\_\_\_\_

\_\_\_\_\_

What Will Happen After \_\_\_\_\_

\_\_\_\_\_

Anything Else \_\_\_\_\_

\_\_\_\_\_

## HOSPICE IS ABOUT LIVING LIFE AS FULLY AS POSSIBLE

When cure is no longer possible, hospice provides the kind of care most people say they want—*comfort and quality of life*. Some people think hospice means you're "giving up" or "there's nothing left for the doctor to do". We don't give up—we change the focus of the plan. The focus now becomes comfort and we work hard at trying to relieve pain and symptoms and help you feel at ease. Hospice is not about giving up but it's about making the most of life.

Hospice and Palliative Care is a health care specialty—just like cardiology (heart) or oncology (cancer) or obstetrics (birthing babies). We are experts (trained and certified) to help patients and families at the end of life. Studies show that there is a special way to care for people at the end of life. Hospice has a team approach for pain and symptom relief, and emotional and spiritual support. The Team works together and includes the patient, family, the patient's own physician, and HospiceCare staff.

### **Family's Role**

As family, you are an important part of the hospice program. We value your input and encourage your involvement. Hospice also supports the family as you manage the changes and difficulties brought on by your loved one's illness. Please do not hesitate to talk to your hospice team about your questions and concerns.

*"You matter because  
you are you.*

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

*We'll do all we can,  
not only to help you die  
peacefully, but to LIVE  
until you die."*

**Dr. Cicely Saunders,**  
Hospice Movement Founder

## **SERVICES PROVIDED WITH HOSPICE**

Services are based on ongoing evaluations and are unique to each patient and family.\*

<b>Medical Services</b>	Hospice Medical Directors partner with your physician (called the Attending Physician) for oversight of care orders.
<b>Nursing Services</b>	Visits for evaluation and support provided on intermittent schedules, as the patient needs them. Services can be increased with special needs or during times of crisis.
<b>On-Call Services</b>	Hospice provides 24 hours/day, 7 days a week On-Call Services. A Nurse will be available to answer questions or provide visits as needed. 1-800-768-8523 See page 11.
<b>Social Workers</b>	Visits and phone calls help with emotional support, caregiving support, financial/legal concerns, advanced directives, organ and body donations and preparing for funeral/memorial services.
<b>Medications</b>	Medicines necessary for the terminal illness are paid for by Hospice. A Pharmacy Card that identifies you as a HospiceCare patient will be used for each covered item and its refill. (A co-pay may apply.) See page 6.
<b>Equipment &amp; Supplies</b>	Durable medical equipment (DME) and supplies necessary for the terminal illness and prescribed by the physician may be provided.
<b>Nursing Assistants</b>	May help with personal care needed by the patient.
<b>Spiritual Care</b>	Chaplains are available to visit and provide spiritual support according to your needs. See page 32.
<b>Counselors</b>	Grief & Loss staff is available to provide counseling to the patient and any family member, prior to a death, as well as up to 1 year following the death. Our Grief & Loss program includes counseling, mailings, support groups.
<b>Volunteers</b>	Trained Volunteers may provide support in the home. Social Workers have more information.
<b>Other Therapies</b>	Sometimes other therapies approved by hospice may be necessary.
<b>Respite</b>	We support patients by supporting the caregivers. Sometimes caregivers need relief. Social Workers can help arrange respite.

\* HospiceCare must be notified and approval must be given prior to therapies, diagnostic/therapeutic procedures (ie CT, MRI, G-tube placement, radiation therapy, chemotherapy, blood transfusions, blood tests, x-rays), consults, emergency room visits, ambulance transport, and hospital admissions or you may be responsible for the cost.

# How are hospice services paid for?

HospiceCare is able to do its work because of a *variety* of funding sources.

The primary source of reimbursement comes from insurance benefits:

## **MEDICARE/MEDICAID**

All Medicare/Medicaid patients who have elected the Medicare or Medicaid Hospice coverage are 100% covered for services relating to the terminal illness. (The Medicare Hospice Benefit is Part A.)

Nursing, Home Health Aide, Social Worker, Chaplain, Bereavement visits are covered.

Pre-approval is required for the following to be covered: medications, treatment, durable medical equipment, basic supplies, lab work, ER visits, diagnostic procedures, hospitalizations, and ambulance transports related to the terminal illness.

### **Exceptions:**

1. For *Medicare* Hospice patients, there is a co-payment of 5% up to \$5.00 on medications related to the terminal illness.
2. For *Medicaid* Hospice patients, there is no co-payment on medications related to the terminal illness.
3. For *Medicare* Hospice patients, there will be room & board charges for non-acute nursing facility care.

### **Note:**

Medications and services NOT related to terminal illness would still be covered by regular Medicare (Part B) or supplemental insurance.

For example, the terminal illness may be End Stage Heart Disease, which would be covered by Medicare Part A (hospice benefit). If there are other illnesses (like diabetes, thyroid, etc), health care for those diseases would still be covered by Medicare Part B.

*Continued on next page.....*

## How are hospice services paid for? (Continued)

### PRIVATE INSURANCE

Your insurance company will be contacted to determine the level of care they will cover. Depending on your insurance coverage, some typical expenses you may incur are hospital bed, wheelchair, bedside commode, oxygen, softcare mattress, walker, medications, room & board at nursing facilities.

Your insurance company will be billed for Hospice services. You will receive a statement from Hospice for charges not covered by your insurance. You will be responsible for meeting your deductible for the year. Full payment for services is appreciated and expected whenever possible; however, you will not be denied services if you are unable to pay.

### PRIVATE PAY

There is a charge for Hospice services. You will receive a bill for these services, and payment is expected. If you are unable to pay the full charge, arrangements can be made through our financial staff and your social worker to work out a payment plan to suit your situation. No one meeting Hospice admission guidelines will be denied Hospice care due to inability to pay.

HospiceCare is committed to caring for individuals regardless of their financial status. Therefore, we also rely on community support: This helps pay for care of patients who don't have enough insurance.

### ***United Way***

### ***Fund-raising***

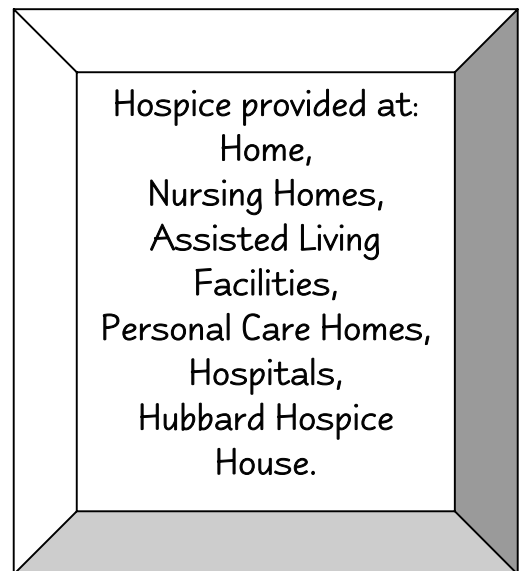
### ***Memorial Donations*** ( Many families choose to suggest memorial donations to HospiceCare "in lieu of flowers".)

Insurance payment rates are going down each year as our expenses go up, and we are relying more on gifts and donations from individuals. So far, we have not had to refuse our services to anyone, no matter what his or her financial status. We hope we can continue to do this, and we know we can if we continue to receive generous support from the individuals we serve and from the community at large. We ask that you please consider the work of HospiceCare when you think about possible gifts and donations.

## WHERE IS HOSPICE CARE PROVIDED?

In most cases, care is provided in the person's home. "Home" may be the patient's residence, a loved one's home, or a care facility like a nursing home or assisted living facility. Home care is the main focus of the HospiceCare program. The HospiceCare commitment to patients and their families is that we will make every effort to provide the support necessary to allow patients to spend their final days at home, with dignity and surrounded by the people they love.

In the **nursing home or other facility**, hospice *adds* to the care provided by the nursing home. The same services offered to patients at home are also offered to patients in facilities. The nursing home staff provides the care and services ordinarily provided by the patient's family, that is, personal care, assistance with activities of daily living, socialization and nursing care including giving medications. The nursing home furnishes room, laundry, housekeeping, and meals. HospiceCare works with facility staff to ensure pain and symptom relief and to provide emotional and spiritual support.



Sometimes, patients need a more intense level of care that requires care in a **hospital** or at the **Hubbard Hospice House** (HospiceCare's short-term inpatient facility). However, HospiceCare staff must authorize this care. Hospice will help you by making arrangements for an inpatient admission. See next page for more information about the Hubbard Hospice House.

**Traveling Patients:** Sometimes after the patient's pain or symptoms are relieved, travel may be possible — to a reunion, to see family, or for vacation. Talk with your Social Worker or Nurse, usually you are able to continue with hospice while you're traveling. We would: make sure you had any medicine you need, still be "On-Call" for any questions, and make arrangements with a hospice in the travel area should a visit be needed.

## More Information about the **Hubbard Hospice House**

If Home Hospice is not possible, for whatever reason, then we must be prepared to provide them with the closest thing to home. At the Hubbard Hospice House, families and friends are

<p><b>Please keep in mind:</b></p> <ul style="list-style-type: none"> <li>√ Hospice house is a <i>short-term</i> inpatient facility.</li> <li>√ Admission and room assignments are based on <i>medical needs</i>.</li> <li>√ You <i>may be responsible</i> for costs that are not related to the Hospice diagnosis.</li> </ul>	
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welcome visitors in the homelike surroundings, and each patient is cared for in a private room setting. The Hubbard Hospice House is staffed by specially trained, highly qualified physicians, nurses, certified nursing assistants, social workers, counselors, chaplains, and volunteers who will provide complete, compassionate care on an around the clock basis.

### **Inpatient Level of Care**

Patients sometimes experience **intense episodes of pain or other symptom problems** that cannot be managed at home. At the Hubbard Hospice House, the hospice physicians visit regularly to help improve symptom management. A nurse provides care 24 hours a day and the staff has been specially trained in pain and symptom management. Once symptoms are controlled, patients return home. Discharge planning begins at admission to Hubbard House.

Medicare and Medicaid cover this level of care at 100% when medically necessary--usually for an *average* of 4-5 days. This level of care may be approved by private insurance on a case-by-case basis, as an alternative to hospitalization.

### **Respite Care**

Respite care is a benefit for Medicare/Medicaid patients that can be provided for a maximum of 5 days. This level of care is to **give caregivers a rest** from the every day physical and emotional strain of caring for a person with a terminal illness. This level of care is usually planned and is based on bed availability. The physician may visit upon admission, but daily physician visits will not be provided.

There is no charge for respite care for those with Medicare/Medicaid coverage. Coverage may vary according to the policy for patients who have other insurance. Respite care can be offered once every 30 days, if beds are available.

### **Routine Care**

Short-term routine care is provided at the Hubbard Hospice House, primarily for those who live alone and **can no longer safely remain at home and require basic room & board care**. Limited beds are available for this level of care. Priority is given to HospiceCare patients. This level of care may be provided for others on a case-by-case basis. There is a charge for room and board that is not covered by insurance. When the patient becomes stable, other arrangements for care need to be considered. The Hubbard Hospice House social worker will assist with discharge planning.

Admissions are approved by the hospice team. The Hubbard Hospice House is Medicare certified and state licensed and there are regulations that govern the use of each level of care. Hospice never denies care based on inability to pay. When admission is necessary, care can be provided to those with no insurance coverage. Arrangements for reduced payment can be made, based on ability to pay.

## We signed up for hospice while in the HOSPITAL, what happens now?

Hospice will start based on the plan that's best for the patient. The Hospice Nurse will work with you and the team to decide the best plan.

### Hospice starting when patient discharged **home** from hospital.

This plan usually is best for most.

#### **Home:**

- When the first visit from a HospiceCare nurse is made in the hospital, it may be several days before your doctor authorizes your discharge.
- When the discharge date is certain, the hospital staff should notify the HospiceCare office.
- If you need medical equipment, it will be ordered and usually delivered before you go home. You will hear from the Equipment Company to arrange for this delivery.
- When you receive prescriptions, you may want to call your pharmacy to make sure the medications are in stock. Arrangements can be made to get the medications from a different pharmacy if necessary. Call HospiceCare if any questions.
- When you arrive home—**no matter what time, please notify HospiceCare by calling: 304-768-8523 or 1-800-560-8523.** Hospice wants to make sure you have everything in place. At that time, you may ask for a visit if you think you need one.
- The first visit is usually made within 24 hours.
- If you are considering a transfer to a nursing home, HospiceCare has contracts with some area facilities. You have the right to choose hospice care for the nursing home resident.

**Don't forget to Call HospiceCare when you arrive home from the hospital!**

### Hospice starting while patient **IN** the hospital:

- Sometimes it's best for hospice to partner with the hospital staff during the hospital stay.
- The hospice team will visit at least every day and work with hospital staff to provide comfort care.

### Hospice starting when **transferred** to the Hubbard Hospice House:

- Some patients require a high intensity of care and will be moved to the Hubbard Hospice House facility.
- The hospital and Hospice House staff will work together to coordinate the move.



## **Urgent/Emergency Care**

### **On-Call Services**

HospiceCare provides on-call services 24 hours a day, 7 days a week. Regular office hours are from **8:00 a.m. to 4:30 p.m. Monday through Friday.** After 4:30 p.m. the answering service will answer your call. If a situation occurs and you need to speak with a nurse during regular office hours or after hours, **please follow these steps to contact a HospiceCare nurse:**

1. Call the HospiceCare number: 304-768-8523 or toll-free 800-560-8523.
2. Tell the receptionist/answering service that you need to talk to a nurse.
3. Give the receptionist/answering service the following:
  - Your name
  - Patient's name
  - Phone number where you can be reached
4. **Remain off the phone to allow the nurse to return your call.**
5. If your call has not been returned **within 30 minutes**, repeat the procedure beginning at step #1.

If there is a problem with the above number, call **304-342-5151** and **identify yourself as a hospice family.**

## Can we call 911?

**We recommend that you call Hospice first** (800-560-8523). Sometimes treatment can be provided in the home and this will prevent an uncomfortable trip to the hospital. Ambulance transport and hospitalization can be arranged quickly by the hospice nurse and your physician if this is needed. If inpatient care is needed, involving the hospice team will avoid a long wait in the emergency room while doctors who do not know you run tests to see if the admission is necessary.

You always have the right to call 911 if an unexpected crisis occurs. However, if you have elected the Hospice Medicare or Medicaid Benefit, the emergency room costs are not covered for the management of your terminal illness. You do have a right to revoke the Hospice benefit to pursue aggressive treatment. **But if you want to continue the comfort-oriented approach that hospice provides, you should call hospice and not 911.**

If you go to the hospital without calling hospice, please tell the emergency room nurse that Hospice is involved in your care. If you want to continue palliative care (or comfort care) in the hospital, please let them know. This may avoid many unnecessary hours in the emergency room. You should also notify hospice as soon as possible. If you want more than comfort measures, you may need to sign papers to revoke the hospice benefit, so that you do not become responsible for the costs. If you have medical problems that are unrelated to your terminal illness, Medicare/Medicaid will pay for the emergency room and hospital stay. Your doctor and the hospice team will be involved to help you with these difficult decisions.

## **Frequently Asked Questions**

### **What is Palliative Care?**

It is care aimed at pain and symptom relief, rather than care aimed at curing.

### **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.

### **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.

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

In the early weeks of care, it is usually not necessary for someone to be with the patients 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. Your Social Worker can help with this.

### **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 curative/aggressive therapy or go on about his or her daily life.

### **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 childbirth, hospice provides its presence and specialized knowledge during the dying process. Actually, research has shown the Medicare patients that chose hospice care rather than other medical interventions when faced with a terminal illness lived on average 29 days longer than those who did not receive hospice care.

## Patient Rights & Responsibilities

The patient or the patient's legal representative on the patient's behalf has a right to the following:

- 1) To have his/her person and property treated with respect.
- 2) To receive information about services covered by the hospice benefit.
- 3) To receive information about the scope of services that hospice will provide and specific limitations on those services.
- 4) To receive effective pain management and symptom control from HospiceCare for conditions related to the terminal illness.
- 5) To be involved in developing his/her plan of care.
- 6) To refuse care or treatment and be informed of the consequences of such.
- 7) To choose his/her Attending Physician.
- 8) To have a confidential medical record.
- 9) To be free from mistreatment, neglect, or verbal, mental, sexual, and physical abuse, including injuries of unknown source, misappropriation of patient property.
- 10) To voice concerns or complaints regarding treatment or care that is (or fails to be) furnished and the lack of respect for property by anyone furnishing services on behalf of hospice.
- 11) To not be subjected to discrimination or reprisal for exercising his/her rights.

## Patient/Family Concerns

While HospiceCare strives to provide the highest quality of services, we realize that from time to time we may not meet your expectations. At any time, you may express your concerns or complaints to a member of your HospiceCare team. Your Nurse or Social Worker may be able to take care of the problem for you.

If not, you may call the Performance Improvement Director at 304-768-8523 or toll free at 1-800-560-8523 during office hours. If you prefer to express your views in writing, you may address your letter to:

**HospiceCare**  
**Attn: Performance Improvement Director**  
**1606 Kanawha Boulevard West**  
**Charleston, WV 25312**

For abuse or neglect, you may also call the West Virginia Department of Health and Human Resources 24 hours a day at 1-800-352-6513.

## NOTICE OF HOSPICE PRIVACY PRACTICES

THIS NOTICE DESCRIBES HOW MEDICAL INFORMATION ABOUT YOU MAY BE USED AND DISCLOSED AND HOW YOU CAN GET ACCESS TO THIS INFORMATION. PLEASE REVIEW IT CAREFULLY.

HospiceCare has established policies to guard against unnecessary release of your health information.

Here is a summary of instances when your health information may be used after you have provided your written consent:

**To Provide Treatment.** Your health information will be shared with other health care professionals in order to provide the best care for you. For example, physicians involved in your care will need information about your symptoms in order to prescribe appropriate medications.

**To Obtain Payment.** The Hospice may include your health information in order to collect payment from third parties for the care you may receive from the Hospice. For example, the Hospice may be required by your health insurer to provide information regarding your health care status so that the insurer will reimburse you or the Hospice.

**To Conduct Health Care Operations.** The Hospice may use and disclose health care information for its own operations in order to facilitate the function of the Hospice and as necessary to provide quality care to all of the Hospice's patients. Health care operations include activities such Quality Assessment and Improvement or at the Hubbard Hospice House we may tell your room number for those that ask for you by name (unless you tell us not to).

Federal privacy rules allow the HospiceCare to use or disclose your health information without your consent or authorization for a number of reasons:

- **When Legally Required.**
- **When There Are Risks to Public Health.**
- **To Report Abuse, Neglect Or Domestic Violence.**
- **To Conduct Health Oversight Activities.**
- **In Connection With Judicial And Administrative Proceedings.**
- **For Law Enforcement Purposes.**
- **To Coroners And Medical Examiners.**
- **To Funeral Directors.**
- **For Organ, Eye Or Tissue Donation.**
- **In the Event of A Serious Threat To Health Or Safety.**
- **For Specified Government Functions.**
- **For Worker's Compensation.**
- **For Research Purposes.** (HospiceCare may, under very select circumstances, use your health information for approved research. The Hospice will ask your permission if any researcher will be granted access to your individually identifiable health information.)

Other than is stated above, the Hospice will not disclose your health information other than with your written authorization, which may be revoked in writing at any time.

## YOUR RIGHTS WITH RESPECT TO YOUR HEALTH INFORMATION

**Right to request restrictions.** You may request restrictions on certain uses and disclosures of your health information. You have the right to request a limit on the Hospice's disclosure of your health information to someone who is involved in your care or the payment of your care. However, the Hospice is not required to agree to your request. If you wish to make a request for restrictions, please contact *your nurse or social worker*.

**Right to receive confidential communications.** You have the right to request that the Hospice communicate with you in a certain way. For example, you may ask that the Hospice only conduct communications pertaining to your health information with you privately with no other family members present. If you wish to receive confidential communications, please contact *your nurse or social worker*. Hospice will not request that you provide any reasons for your request and will attempt to honor your reasonable requests for confidential communications.

**Right to inspect and copy your health information.** You have the right to inspect and copy your health information, including billing records. This request may be made to *Medical Records*. If you request a copy of your health information, the Hospice may charge a reasonable fee for copying and assembling costs associated with your request.

**Right to amend health care information.** If you or your representative believes that your health information records are incorrect or incomplete, you may request that the Hospice amend the records. That request may be made as long as the information is maintained by the Hospice. A request for an amendment of records must be made in writing to *Medical Records Supervisor*. The Hospice may deny the request if it is not in writing or does not include a reason for the amendment. The request also may be denied if your health information records were not created by the Hospice, if the records you are requesting are not part of the Hospice's records, if the health information you wish to amend is not part of the health information you or your representative are permitted to inspect and copy, or if, in the opinion of the Hospice, the records containing your health information are accurate and complete.

**Right to an accounting.** You or your representative have the right to request an accounting of disclosures of your health information made by the Hospice for any reason other than for treatment, payment or health operations. The request for an accounting must be made in writing to *Medical Records Supervisor*. Accounting requests may not be made for periods of time in excess of six years. The Hospice would provide the first accounting you request during any 12-month period without charge. Subsequent accounting requests may be subject to a reasonable cost-based fee.

**Right to a paper copy of this notice.** You or your representative has a right to a separate paper copy of this Notice at any time even if you or your representative have received this Notice previously. To obtain a separate paper copy, please contact *HospiceCare*. You may access it on our website: [www.hospicecarewv.org](http://www.hospicecarewv.org).

## DUTIES OF THE HOSPICE

The Hospice is required by law to maintain the privacy of your health information and to provide to you and your representative this Notice of its duties and privacy practices. The Hospice is required to abide by terms of this Notice as may be amended from time to time. The Hospice reserves the right to change the terms of its Notice and to make the new Notice provisions effective for all health information that it maintains. If the Hospice changes its Notice, the Hospice will provide a copy of the revised Notice to you or your appointed representative. You or your personal representative have the right to express complaints to the Hospice and to the Secretary of Health and Human Services if you or your representative believe that your privacy rights have been violated. Any complaints to the Hospice should be made in writing to *the Medical Records Supervisor*. The Hospice encourages you to express any concerns you may have regarding the privacy of your information. You will not be retaliated against in any way for filing a complaint.

**CONTACT PERSON:** Kitty Kiser, RHIA, CCS, Medical Records Supervisor and Privacy Officer 1-800-560-8523.

**EFFECTIVE DATE:** April 1, 2009

## **PATIENT CARE INFORMATION FOR HOSPICE FAMILIES**

Your primary nurse will provide you with educational materials and teach you how to care for your loved one so that you can manage most situations on your own. Our nurses are available to coach you by phone or to make an unscheduled visit, if necessary. During periods of medical crisis, your nurse will evaluate the need for increased nursing support.

If respite or caregiving is needed, your social worker can work with you to make arrangements or provide you with the names of agencies in our area that employ caregivers you may hire. The social worker can also talk with you about your options for inpatient respite care.

### **PAIN RELIEF**

Pain can affect people in many ways. It can keep them from being active, from sleeping well, from enjoying family and friends and from eating. Pain can also make people afraid, anxious or depressed. The hospice team will evaluate physical, emotional and spiritual pain. Working with you, they will provide treatment, care and support to improve pain control and quality of life.

Different types of medications help with different kinds of pain. It is important to describe what the pain feels like and what makes it better or worse. Untreated pain is harder to relieve, so always report pain to your nurse. Your nurse will teach you how to report the intensity of the pain using a 0-10 scale, a Faces scale, or with words.

#### **Keep a written record:**

- ✓ when pain happens—anything that may cause it or make it worse
- ✓ how bad is the pain
- ✓ when medicine taken and how long it takes to help
- ✓ any side effects-nausea, drowsiness, constipation, etc

**When pain is there all the time, it is best to take the pain medication on a regular schedule, even if you are not having pain when the next dose is due.** You should not feel drowsy when your body adjusts to the medication. You may sleep more when a medication is changed or increased, but only for 1-2 days. If you are on a long-acting medication, you should also have a short-acting medicine that can be taken “as needed” if you have more pain.

## PAIN RELIEF (continued)

**Addiction does not develop** when pain medication is used properly for pain relief. Other medicines may be prescribed to improve pain relief such as antidepressants that help with nerve pain and anti-anxiety drugs to help relieve feelings of fear. Make sure you understand the directions for each medication and its purpose. Your hospice nurse will explain your medications to you.

Your nurse has orders from your doctor and can make changes to improve your pain control. Your written record will help the nurse adjust the schedule and doses to make you more comfortable.

## OTHER COMFORT MEASURES

- Helping a patient change position or turn can relieve stress and strain on the body's bones, muscles, and skin.
- Warmth and massage of a hurting area can help in relaxation of the



person and the surrounding muscles.

Note: Do not place heating pads near/on medication patches.

- For very severe pain, an ice cube massage can also relieve painful spasms. Many times it depends on the person's concept of pain and different methods may work better at different times.
- Slow, rhythmic breathing can help the patient to let go of pain and draw in pleasant thoughts.



- Music, pleasant aromas, and thoughts about other experiences can help a patient feel more comfortable. The family may provide music/readings that are important to the person. Any of the staff will help you search for methods that work for you and the family.

## **Problems with Swallowing**

As your loved-one becomes weaker, the swallowing reflex may also weaken. At first, you may be able to crush medications and give them in applesauce. Some medicines cannot be crushed and may need to be changed. Your hospice nurse will help you with these changes. There may be some medications that are no longer important at this final stage of the illness. Many medicines to control pain and other symptoms can be given under the tongue in a concentrated form. When given this way, they are absorbed directly within the mouth and not through the digestive system.

## **Relieving Dry Mouth**

When unable to drink at the end of life, the main source of discomfort is dry mouth. Initially, you may be able to moisten the mouth with water, but this can cause coughing and choking as the patient nears death. You can apply a small amount of olive oil (or other vegetable oil) to the tongue and lips with a cotton tip applicator or toothette.



## **NUTRITION**

Nutrition is an important part of our lives from the time we take our first breaths as infants. Our culture places much importance on meal planning, calorie counts, and social interactions during meal times. Often feeding and preparing meals for a loved one is a way of communicating love, concern, and caring in a direct and non-verbal way.

Whenever anyone is ill, his or her appetite decreases whether the illness is the flu, an injured ankle, or a cancer-related process. The body's needs for high calorie and protein foods are altered because of decreased activity, exercise, and general metabolic rate. Nutritional foods are important for adequate healing of any injured body part; however, that is not always possible with hospice patients.

### **Patients have less appetite with:**

Nausea and vomiting	Weakness
Constipation	Fatigue
Bowel tumors	Medications
Bowel obstruction	Chemotherapy
Liver cancer	Radiation
Pancreatic cancer	Bleeding gums
Pain	Dental problems

Many of the people hospice cares for are dealing with a decrease in appetite, nausea, vomiting, pain, and constipation. The most common problems many family members face are finding the right kind of foods and difficulty in getting the patient to eat. Too often this "food struggle" can develop into a friction that can interfere with their open communication with each other. The HospiceCare staff believes that this struggle can be avoided by allowing patients to eat what and when they want.

When faced with a terminal illness, an individual begins adjusting the priorities of their life and may desire to spend energy on activity and relationships, rather than on food. Our bodies are much wiser than we think and will give us messages about what we need. The terminally ill person is facing the end of life, and the sustaining value of food is often not important to them. Many times the disease process affects taste buds and will make foods taste bland, salty, or sour.

## TRY THESE NUTRITIONAL HINTS:

- Eat small, frequent meals (at least every 2 hours).
- Add sauces and gravies whenever possible.
- If not able to take in many fluids, offer liquids that are higher in calories, such as: regular soda pop, lemonade, milkshakes, Kool-Aid, fruit drinks, fruit juices.
- Add extra jelly, butter, margarine, sour cream, mayonnaise, and peanut butter to foods.
- Use milk or half and half instead of water when making soup, cereals, instant cocoa puddings, and canned soups.
- Have snacks to eat. Nuts, dried fruits, candy, popcorn, crackers and cheese, ice cream, granola, and Popsicles all make good snacks.
- Eat chicken and fish that are breaded and higher in calories.

### **Fortified Nutritional Milkshake**

1 Package Instant Breakfast (flavor of your choice)  
8 oz. Whole Milk (or Half & Half)  
½ cup Vanilla Ice Cream (or other preferred flavor)  
2 tsp. Powdered Milk

Blend well. This can be consumed over a period of several hours or used immediately. Try putting it in the freezer for a short time. It will be the consistency of a "frosty" and can be eaten with a spoon. Great! You can add fresh strawberries or bananas.

510 calories 28.7 gm protein

### **Add calories to Milk:**

1 quart whole milk  
1 cup powdered milk

Mix and refrigerate.

## **What Happens When He Can No Longer Eat or Drink?**

A decision that has to be made when a person can no longer eat and drink is whether artificial nutrition or hydration should be provided. Families are often concerned that their loved-one might starve to death. When a person has had a stroke and is expected to recover, a feeding tube may be necessary. However, when a feeding tube is inserted in someone who is dying, this may actually cause suffering. Rather than improving quality of life by providing nourishment, the feeding tube may result in more difficulty breathing, diarrhea, and other discomforts

Many studies show that feeding tubes and IV fluids do not increase comfort at the end of life. Most of these studies have been conducted on cancer patients, but they apply to many different terminal illnesses. The results of some studies lead us to believe that artificial nutrition can actually cause more complications such as infections, which may result in an earlier death.

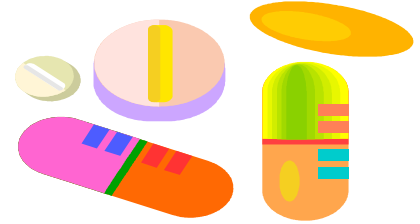
The Hospice Team can help you consider the benefits and burdens of treatments, so that you can make the best decision in the context of your own personal values. These decisions are very difficult and family members may not always agree. Sometimes a time-limited trial may be offered to allow you to see if the treatment does have some benefit. When you are trying to make a decision, you may want to involve your pastor, rabbi, or spiritual advisor to help you. The hospice chaplain may also help you work through any spiritual concerns you have as you try to make the decision that is best for your loved-one.

### **Some Potential Benefits of Not Using Tube Feedings and IV Fluids Near Death**

<u>Effect on the Body</u>	<u>Benefit</u>
Less fluid in the lungs	Easier to breathe
Less fluid in the throat	Less need for suctioning
Less pressure on tumors	Less pain
Less frequent urination	Less risk for bedsores
Increase in the body's natural pain-relieving hormones	Increased comfort and less pain

*From Handbook for Mortals by Lynn and Harrold*

## Medication Safety



Medications can change and this may be confusing. Therefore, we will help you keep a written record of what is being given. This medication record should list the medicine, when to give them and what they are for (pain, shortness of breath, constipation, etc).

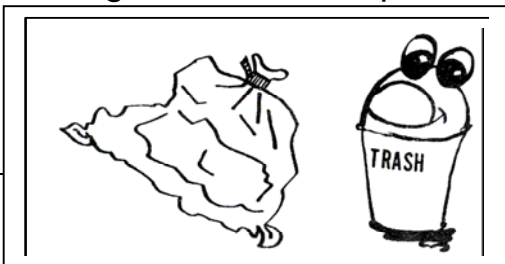
Make sure the medications are given as directed. The medications are ordered for the *patient*. It is very important that no one else takes these medications. Store them in a safe place away from children and visitors. You may request childproof caps if you have children in the home. Know how long your medicine should last before you need a refill. If you think someone else is taking the medication, or if any of your drugs are missing, talk to a member of the HospiceCare team. Drug diversion (someone other than the patient using his/her medication) can be grounds for discharge from hospice.

West Virginia has laws about medications, especially medications known as narcotics—Oxycontin, oxycodone, morphine, etc.). HospiceCare must follow these laws. This means that our nurses and doctors must make sure that we monitor and account for the amount of narcotics used. To monitor: We will be asking questions. We will need to see your medications. We'll need to know if any medication is spilled or missing. We may recommend a lock-box to store your medications safely. Our primary goal is for our patients' symptoms to be relieved. But we also have regulations that we must follow. Thank you for understanding.

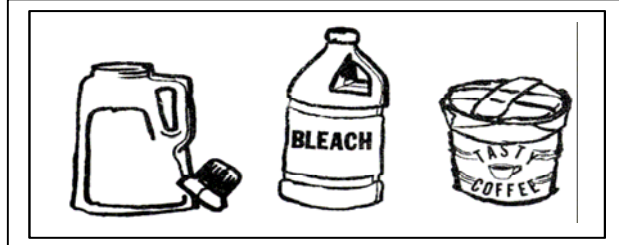
The nurse will teach about disposing of unused medications.

# Infection Control

1. Your family member may have less resistance to infection. Any visitors with a fever, cough or recent gastro-intestinal distress should delay visits for 24 hours or until the symptoms have gone, if possible.
2. **Your best precaution is GOOD HANDWASHING** before and after you do any care with the patient. Wear gloves if you handle urine, stool, blood, or any other body fluids.
3. Normal washing and drying of bed linens kills most organisms in a household.
4. One hour of sunlight with good washing will kill additional germs on objects, if necessary.
5. Personal care items, disposable briefs, continence pads, and bandages should be placed in two bags for normal disposal.



6. Any sharps should be put in a firm container (coffee can or hard plastic detergent bottle) and taped shut.



7. A solution of one part chlorine bleach to ten parts of water should be used to clean up any spots of blood or body fluids in the bathroom or on other surfaces.
8. Generally, a patient and the family are resistant to most organisms in a home. Your nurse will teach you specific precautions, if necessary.

## Fall Safety

1. Throw rugs and cords across walkways can trip a weakened person.
2. Use non-skid mats or a chair in the bathroom. Safety devices are available.
3. The nurse will give you specific instructions to make lifting and transfers easier safer. Let the nurse know if you see increasing weakness in the patient.
4. Changes in strength put both of you at risk for injury, so use precautions. As weakness develops, make sure a person can stand before you lift them by yourself. If they fall to the floor, cover them and call a neighbor for help rather than trying to lift them. The bathroom can be modified to make transfers and personal care safer. At night leave a light on. A bedside commode can help prevent hurried trips to the bathroom when falls commonly happen.

## Special Considerations for Confused Patients

If your loved-one has a condition that causes mental confusion, there are additional safety measures that you should follow.

- Keep all medications out of the patient's reach.
- Keep all dangerous items away from the patient, e.g. guns, knives, scissors, pins, power tools, irons, hair dryers, lighters, matches, cigarettes.
- Block access to exposed hot water pipes, heaters, fires.

## Fire Safety

1. **Oxygen can be very safe in the home but must be separated from open flame, such as cigarettes and gas heaters.** Specific precautions will be taught to you when needed.
2. Have smoke alarms installed on each level of your home and right outside your sleeping area.
3. Always have two exits available from your home. In case of a fire and your loved one can no longer walk, lowering them to the floor gently and pulling them on a blanket can generally be successful. Protect both of you from smoke inhalation with a wet towel placed over the mouth until help arrives.

## Disaster Safety

1. Always have someone outside of your home that knows your needs. Encourage them to watch the weather/news for you and contact someone if you are at risk for a disaster like a tornado, chemical spill, or flood.
2. Learn about your community's **warning signals**: what they sound like and what you should do when you hear them. Contact your local emergency management or civil defense office and American Red Cross chapter for more information.
3. Have a **Plan**: where to evacuate? What to do if water, gas, electricity, phones cut off?
4. **Utilities**: Locate the main electric fuse box, water service main, and natural gas main. Learn how and when to turn these utilities off. Teach all responsible family members. Keep necessary tools near gas and water shut-off valves. Remember, turn off the utilities only if you suspect the lines are damaged or if you are instructed to do so. *If you turn the gas off, you will need a professional to turn it back on.*
5. Have an **Emergency Kit**:
  - A three-day supply of water (one gallon per person per day) and food that won't spoil.
  - One change of clothing and footwear per person, and one blanket or sleeping bag per person.
  - A first aid kit that includes your family's prescription medications.
  - Emergency tools including a battery-powered radio, flashlight and plenty of extra batteries.
  - An extra set of car keys and a credit card, cash or traveler's checks.
  - Sanitation supplies. Special items for infant, elderly or disabled family members.
  - An extra pair of glasses.
  - Keep important family documents in a waterproof container.

### **If disaster strikes:**

- Remain calm and patient. Put your plan into action.
- Check for Injuries: Give first aid and get help for seriously injured people.
- Listen to your battery-powered radio for news and instructions.
- Evacuate, if advised to do so. Wear protective clothing and sturdy shoes.
- Check for damage in your home.

## THE FINAL DAYS—WHAT TO EXPECT

The HospiceCare team can help prepare you for the final days. This preparation will be provided as specific issues or concern arise. Here is some information that can also be useful. Remember, no matter how well prepared you are, it is natural to be confused, upset, and unable to read or follow instructions for a period of time during the final days or following the death.

***Be tolerant with yourself. Take your time. You will do just fine.***

When a person enters the final stage of life, two things begin to happen:

**Physically**, the body begins the final process of shutting down, which is when all the systems cease to function. Usually this is an orderly series of physical changes, not medical emergencies. These physical changes are normal and natural and usually require comfort measures only.

**Emotionally and spiritually**, your loved one has been working through the process of letting go of this life. There may be relationship or spiritual concerns that need to be addressed. It is normal to have these concerns. Often they can resolve themselves but may need help from a counselor or chaplain.

The experience we call death occurs when the body completes its natural process of shutting down both physically and spiritually.

### **Signs, Symptoms, and Responses**

These are normal signs you may notice during the dying process. Keep in mind every death is unique but generally follow some or all of the following signs.

**Coolness** – The patient's hands, arms, feet and then legs may be increasingly cool to the touch. The color of the skin may change, turning dark or purplish. This is due to the slowing of the circulation preserving blood flow to vital organs.

**Sleeping** – The person may spend an increasing amount of time sleeping. He may be difficult to arouse and not respond to you, as he would have in the past. Sit with your loved-one; hold his hand, speak to him softly, as you normally would even if he doesn't seem to hear you. Hearing is the last sense to leave the body.

**Difficulty Swallowing** - You may notice the patient may cough or choke when drinking or eating. This is usually one of the first signs that swallowing is becoming difficult. Then the patient seems to forget how to swallow, not knowing what to do with the pills you put in his mouth.

Make sure he is sitting up as much as he can or the head of the bed is elevated. This prevents choking and food or fluids from going into the lungs which can cause pneumonia.

At some point, it will be necessary to stop feeding him because he is unable to swallow anything. Usually the patient isn't hungry at this point. It is a very difficult time for families because they are thinking, "He will *die* if he doesn't *eat*." Remember: He isn't *eating* because he is *dying*.

**Disorientation** – The person may seem confused about time, place, and people, even those who are close he may not recognize. Identify yourself by name rather than asking the person to guess who you are. Speak softly, clearly, and truthfully when you need to communicate something important for the patient's comfort. Say, "It's time to take your medication", explaining the reason, "so you won't begin to hurt."

The person may see and speak to persons or loved ones who have already died. This, too, is common and usually isn't frightening to the patient. Be careful not to contradict, belittle, or argue about what the person claims to have seen or heard as it may cause agitation. Even though you cannot see or hear what the patient sees or hears, it is real to your loved-one. Affirm his experiences. If your loved one does become frightened, gently explain that the experiences are not unusual. The chaplain may help with this anxiety or fear.

**Incontinence** – The patient may lose control of his bladder and/or bowels as the muscles begin to relax. The nurses and nursing assistants will teach you how to help keep your loved one clean and comfortable.

**Congestion** – The person may have gurgling sounds coming from the chest that may become very loud. This normal change is due to secretions that gather in the back of the throat or in the lungs.

Suctioning usually only increases the secretions and causes great discomfort. Instead, gently turn the person's head to the side to drain the secretions. You may also wipe the mouth with a moist cloth and clear the secretions inside the mouth with a toothette or swab. Your nurse may also supply medications that can help dry these secretions.

**Restlessness** – The patient may become restless, pulling at bed linen or their clothing. Sometimes they may reach up in the air or look as if they are doing some activity with their hands. It looks like they are dreaming with their eyes open.

Do not interfere with or try to restrain such motions. Speak to him in quiet, natural tones. Play music he likes or read to him. If the restlessness becomes severe, you will want to give the prescribed medications. Your nurse will assist you with this.

**Decreased urine** – 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. It doesn't always mean his kidneys are "shutting down." This is natural and does not mean the patient needs to drink more.

**Breathing Pattern Change** – The person's regular breathing pattern may change, becoming irregular. His breathing may start out deep and labored, gradually becoming more shallow with periods of no breathing (or apnea) for 5 to 30 seconds or up to a minute. This is called "Cheyne-Stokes" breathing. The person may also experience periods of rapid, shallow, or panting-like breathing. These patterns are very common and normal.

Elevating the head of the bed and/or turning the person on his side may help. These breathing changes usually don't seem to bother the patient but can be distressing to the family.

**Withdrawal** – The person may seem withdrawn and not interested in his surroundings. This doesn't mean he can't hear you or doesn't want to talk. He just doesn't have the energy to interact.

Since hearing remains to the end, speak to your loved one in your normal tone of voice and identify yourself by name. Let him know when you are going to touch him or provide care so it won't startle him.

**Decreased Socialization** - Your loved one may withdraw from others. Often maintaining a quiet, peaceful environment is best. The person may want to be with only a very few people in the last few days. It does not mean you are not loved or are unimportant. His body requires his energy for the changes he is going through at this time.

**Giving Permission** - Giving your loved one permission to "go" is difficult. Even though it brings prolonged discomfort, sometimes a dying person will try to hold on in order to be sure that those who are going to be left behind will be all right. Let him know that it is okay to go and assure him you are okay but you will miss him. Giving him permission can be one of the greatest gifts you can give your loved-one.

**Saying "Good-bye"** - When the person is ready to die and you are able to let go, then it is time to say "Good-bye." Saying "Good-bye" is your final gift of love, for it achieves closure. If it is helpful, you can lie beside him or hold his hand and then say everything you need to say. It may be as simple as saying, "I love you." Or you may need to say, "Forgive me", "I forgive you", or "Thank you". You may want to include favorite memories, places and activities you've shared. Tears are a normal and natural part of saying "Good-bye." Tears do not have to be hidden. They express your love and help you let go.

**When Death Occurs** - The signs of death include: no breathing, no heartbeat, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, jaw relaxed, and mouth slightly open.

- If you feel death has occurred, call HospiceCare and tell the receptionist you need to speak to the nurse immediately. The supervisor will contact your nurse.
- If it is after 4:30 PM or the weekend, call the main number (304-768-8523 or 800-560-8523) or the answering service (304-342-5151). Let them know your family member has died. Leave your name, the patient's name, and your phone number. Stay off the phone to keep the line open for the nurse to return your call.
- Your nurse will call you and let you know she is on her way. If you haven't received a call from the nurse in 15 minutes, call HospiceCare again.
- The nurse will examine the patient, pronounce death, and call the funeral home. She will wait with you until the funeral home arrives and assist the attendants when they arrive. The funeral home attendant will make an appointment with you to make final arrangements for the service.
- The nurse will contact your physician and HospiceCare will make arrangements for the equipment to be picked up.
- Later, hospice team members will call and check on you. And you can always call us.

***This time can be very overwhelming but your hospice team will help you.***

## **SPIRITUAL CARE:** ***What this means and how HospiceCare can Help***

Serious illness often makes people think more about their spiritual and religious values and beliefs. In one survey conducted among people with limited life expectancy, over 50% of those who had no previous involvement with religion wanted to talk about spiritual issues.

Spiritual health is recognized as an important part of hospice care. However, spirituality means different things to different people. Many people have unanswered questions and uncertainty related to spiritual issues when they are facing a limited life expectancy and may need to talk about those issues with someone they can trust.

Spiritual care may include:

- Participating in religious rituals of faith that bring strength and comfort (for example: communion, prayer, baptism, etc)
- Examining personal beliefs and life contributions
- Exploring beliefs about what happens after death
- Reaching a level of peace with life choices
- Discovering meaning and purposes in the midst of dealing with terminal illness.

HospiceCare is NOT affiliated with any religion. Your hospice team will not impose their beliefs on you, but they may ask you about what is important to you and what you believe. The hospice team will respect your spiritual values. You may prefer to reflect and meditate about spiritual issues privately, talk with close family members, or talk with one of the members of your hospice team.

If you would like to talk to a spiritual counselor, HospiceCare has staff chaplains who are available upon request. If you prefer, a referral can be made to a spiritual counselor from the faith tradition of your choice in the community.

# Living With Loss and Grief

## What to Expect When You are Hurting

**Emotional Reactions** -- You may find yourself experiencing some of the following normal emotional reactions to grief:

- Unable to grasp the reality of the death.
- Feeling guilty/responsible for what was or was not done.
- Anger at your loved one for "leaving you"
- Anger at God for allowing it to happen.
- Anger at the medical community for not providing a cure.
- Anger at the world for being "better-off" than yourself.
- Frequent and unexpected crying episodes.
- Inability to cry.
- Feeling isolated and lonely.
- Preoccupation with images of the deceased.
- Irritability with friends/family who try to be helpful.
- Idolization of the deceased.
- Feelings of unreality in terms of self with the world.

**Physical Reactions** -- Although symptoms of grief can often be mistaken for health-related problems, the agency does not recommend that you assume any or all of the more commonly experienced grief reactions listed below be taken lightly. Should you feel that any of these problems are disease related, please consult your family physician.

- Tightness in throat or heaviness in chest.
- "Hollow" or empty feeling in stomach.
- Increased/decreased appetite.
- Change in weight - loss or gain.
- Difficulty falling to sleep or staying asleep.
- Decreased energy.
- Lethargy.
- Breathing/stomach distress associated with anxiety.
- Restlessness, confusion.
- Inability to concentrate or stay on task.
- Increased awareness of things around that relate to grief/sadness.
- Decreased interest in life and surroundings.

## **Help for the Hurting**

If you feel that you are having problems dealing with any of these reactions, you may find it helpful to discuss it with someone. Very often a friend who has experienced a similar loss may be very comforting and understanding. You may also feel that you want to talk to someone with professional training in this area. HospiceCare has professionals with whom you may explore your grief experiences and verify the sanity, reality, and meaning of your grief.

## **Face to Face with Death**

All of us come face to face with death, losing someone who is very near and dear to us. Some of us have learned to accept death as a part of life because we were exposed to dying as children and were taught how to handle the feelings. Others are adults when they experience their first loss and the shocking reality of death.

## **Mourning and Memories**

No matter what our experiences have been, we all go through a period of mourning. It is a process by which we work through the loss, regaining a sense of balance and reintegration in our own lives. Our feelings must come to the surface even though it is often painful to us and those around us. The crux of the mourning process deals with memory. By consciously working through memories to the present, we convert the painful reality of death to a comforting memory.

## **The Length of Grief**

Grief affects us mentally, physically, spiritually, and emotionally, but sometimes others expect us to return to "normal" in a few weeks or months. We could assume one year to be the minimum duration of mourning and two to three years the average. Variations depend on the experience and temperament of the bereaved and the quality and duration of the relationship with the deceased.

Grief & Loss counselors are available to provide counseling to the patient and any family member, prior to a death, as well as up to 1 year following the death. Our Grief & Loss program includes counseling, mailings, support groups.





**What Am I  
Supposed to Do  
Now?**

Reprinted by Kanawha Hospice Care, Inc. d/b/a HospiceCare  
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## Purpose of this Booklet

The purpose of this booklet is to provide a checklist of the many tasks--legal, social, and financial--that must be carried out after a family member dies and the funeral has taken place. The emotional crisis brought on by the death of a loved one makes it difficult to remember all the details that need to be attended to. We hope this booklet will serve as a reminder, providing sufficient information without being overwhelming.

We suggest the following steps in the use of this booklet:

**Step 1:** Since some of the suggestions given may not apply to your family, the first step is to read through the booklet and make a check to the left of those items that **do** apply. (You want to mark out the remaining items.)

**Step 2:** Decide which family member or friend is going to do which task; then put that person's initials in the blank at the end of that item. Delegating some of the tasks can help reduce the stress for the family members most closely involved.

**Step 3:** As each task is completed, enter the completion date in the far right blank.

Some tasks need to be attended to as soon as possible after the death. These we have labeled "Top-Priority Tasks." The less urgent tasks are divided into three categories: legal, financial, and social. Naturally, there is some overlapping among these classifications.

## Top Priority Tasks

\_\_\_ We hope you had someone keeping a list of people who attended the funeral or made a visit, those who brought food, sent flowers or memorials, or performed other kindness. If not, try to compile such a list from memory as soon as possible. \_\_\_\_\_

\_\_\_ Begin the process of probating the Will. (See page 40 for an explanation of this process.) \_\_\_\_\_

\_\_\_ Return any rented sickroom aids and request a refund for the unused portion of the rental fee. \_\_\_\_\_

\_\_\_ Obtain death certificates from the funeral home and/or the County Clerk in the county where the deceased resided. You will need one for each asset (that is, for each piece of property, Life Insurance Policy, Bank Account, Certificate of Deposit (CD), Individual Retirement Account (IRA), etc.) owned by the deceased. If the funeral home does not provide enough certificates, the County Clerk can supply additional copies. (Most families require about six copies.) \_\_\_\_\_

\_\_\_ If the deceased had a Life Insurance Policy, notify the Insurance Company of the death and ask the representative what procedure you need to follow.

**NOTE:** The Life Insurance cannot be touched by creditors, unless it is payable to the estate. \_\_\_\_\_

## Legal Tasks

\_\_\_\_\_ The following information is provided to acquaint families with the process and some of the terminology involved in settling an estate through the office of the Fiduciary Supervisor of the county in which the deceased resided.

### **Definitions**

#### **The Will:**

A document that specifies how an individual wishes his/her possessions to be disposed of after death. It must be signed by two witnesses who are not mentioned in the Will.

#### **Intestate:**

"Without a Will." When no Will can be found after a death, the estate is divided among the family members according to provisions made in the West Virginia law of intestate succession.

#### **Executor of the Will:**

The person designated in the Will to be responsible for settling the estate. If you are the person so designated, you may need to pay a fee and post a Bond. You will then receive testamentary letters that will empower you to handle the affairs of the estate.

The duties of the Executor include:

1. Establishing a checking account for the estate. (A banker will tell you how.)
2. Making at least four inventories of the estate, to be submitted to the Fiduciary Supervisor.
3. Paying creditors and, in some circumstances, selling property.

#### **Administrator of the Estate:**

The person handling the estate of an individual who died intestate (without a Will). If you are the administrator, you have the same tasks as those described for the Executor. Instead of "testamentary letters", you will receive "letters of administration" empowering you to take care of the affairs of the estate and you will have to post a Bond.

#### **Taxes:**

\_\_\_\_\_ State and Federal Income Tax returns for the deceased must be filed at the usual time, and any real estate belonging to the deceased must be listed for both County and City property taxes. There is also the possibility of State Tax and Federal Estate Tax.

\_\_\_\_\_ For tax purposes, keep receipts of all bills for medical and funeral expenses and for grave markers, in addition to the usual records of deductible expenses and contributions. You will also need a record of any accounts outstanding in the name of the deceased on the date of death. For further tax information, consult your **lawyer** or **tax preparer** or call the **Internal Revenue Service** and the **State Department of Tax and Revenue**.

**NOTE:** Tax forms are also available at the **Public Library**.

**Deeds and Titles:**

Jointly owned real estate in West Virginia automatically goes to the spouse, regardless of the Will, provided two conditions are met: **(1)** that the property was acquired during the marriage and **(2)** that both names appear on the deed.

\_\_\_ If you have Mortgage Insurance and the deceased's name was listed on the mortgage to your home, notify the company that holds the Mortgage Insurance and ask what procedure to follow. \_\_\_\_\_

\_\_\_ Titles on any vehicles belonging to the deceased must be transferred to the new owner, who will have to pay off any remaining indebtedness. \_\_\_\_\_

**NOTE:** The transfer of title requires that the certified copies of the testamentary letter or letter of administration be taken to the West Virginia Motor Vehicles Agency. You will also need the registration card and cash to pay the transfer fee.

\_\_\_ Whenever there is a change in the title to a car or a piece of property, the Insurance Company must be notified.

**Your Own Will**

\_\_\_ Survivors need to review their Wills, to see if any changes should be made. \_\_\_\_\_

## Financial Tasks

### **Bank Related:**

\_\_\_ Any bank account in which the name of the deceased appears will be frozen at the time of death. In order to unfreeze the account so that it can be closed, you need to file testamentary papers with the Fiduciary Supervisor of the County Commission. (If the account is a joint account, with rights of survivorship, this does not apply.) \_\_\_\_\_

\_\_\_ If, at the time of death, a safety deposit box was rented solely in the name of the deceased, the box cannot be opened until the executor has obtained testamentary papers. (If the safety deposit box was rented jointly, with rights of survivorship, this does not apply.) (If the Will is present in the box, a bank official must be present.) \_\_\_\_\_

\_\_\_ If you no longer need the safety deposit box after it has been opened, tell the banker and ask that a prorated refund on the annual rental fee be returned to the estate. \_\_\_\_\_

### **Insurance Related**

\_\_\_ **Life** insurance has been discussed under "Top Priority Tasks." Now you should review your own life insurance policies with an insurance agent that you trust and make necessary changes in beneficiaries or coverage. \_\_\_\_\_

\_\_\_ **Health** insurance. Phone or write each company with which the deceased had a policy. After informing the agent of the death, ask what changes need to be made in the policy and find out if you are due a refund on the unused portion of the premium. At the same time, request forms to begin the process of obtaining reimbursement for the medical expenses incurred by the deceased. \_\_\_\_\_

**Mortgage** insurance is discussed in the section on "Deeds and Titles".

**NOTE: Be sure to complete all necessary forms within one year of the death.**

### **Survivors' Benefits**

\_\_\_ If the deceased had been employed, the employer's personnel department should be able to give you information about retirement benefits, group life insurance, or payments for unused vacation or sick leave to which you may be entitled. Ask about each of these specifically, and also about CD's and IRA's that the deceased might have had with the firm. What are the benefits, and to whom are they payable? \_\_\_\_\_

\_\_\_\_ Most families are eligible for survivors' benefits from Social Security, the Veterans Administration, and/or the Civil Service Administration. It is not within the scope of this booklet to give all the eligibility requirements for each of these programs; but if you think you may be eligible, call the agency and inquire.

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\_\_\_\_ It is important that you make application for benefits as soon as possible. Under certain circumstances, benefits start from the date the application is received by the appropriate government agency and not from the date of death. Mail all letters and applications "Registered Mail--Return Receipt Requested."

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\_\_\_\_ Although funeral directors are required to notify the Social Security Administration of deaths, you should not expect the agency to get in touch with you. Call the Social Security office, and you will be told how to apply for benefits. When you make this call, be prepared to give the following information:

1. Name of the deceased.
2. Whether the deceased was receiving Social Security; if so, the claim number. (Never cash checks that have the name of a deceased person on them, even if that person was your spouse and the check was issued to you jointly. Such checks should be returned promptly to the Social Security Administration, so that they can be re-issued in the correct amount.)
3. Date of death.
4. Names of any previous spouses, and their claim numbers.

\_\_\_\_ Let the Social Security representative advise you as to the next steps you must take. In most cases, you will be asked to furnish copies of the following items:

1. Marriage Certificate.
2. Birth Certificates of spouse and children.
3. Any adoption papers.
4. Any military discharge papers.
5. The Death Certificate.
6. Social Security numbers for the deceased and his/her spouse, children, and dependent parent(s).
7. If deceased was employed, the W-2 Forms for the last two years.

\_\_\_\_ If the deceased served in the armed forces at any time, phone the Veterans' Administration and ask for an application for survivors' benefits. You will need to give your relationship to the deceased and his/her name in full, branch of service, dates of service, service number, and date of death. If you need help in completing the form when you receive it, check with the HospiceCare office.

\_\_\_ Dependents of veterans are asked to supply:

1. The original Marriage Certificate or a certified copy.
2. Children's Birth Certificates--originals or certified copies.
3. Records of all sources of income.
4. If you are eligible for Social Security, the award letter indicating the amount of your benefit.
5. Proof of service records, unless you or your spouse was receiving benefits at the time of the death.

\_\_\_ To learn if your family is eligible for Civil Service Benefits, get in touch with any agency of the federal government where the deceased was ever employed.

Letters must be written to change or cancel:

**Credit cards:**

\_\_\_ When your next bill comes, mail the destroyed card back to the company, along with your payment. If you want to continue the account, write a letter requesting that a new card be issued in your name alone.

List Credit Cards Here

<u>Company</u>	<u>Account Number</u>
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

**Auto Insurance:**

\_\_\_ If this was in the name of the deceased, and you have disposed of the car or no longer plan to drive it, request a prorated refund on premiums already paid.

**Memberships in clubs, fraternal orders, etc.:**

\_\_\_ Request a prorated refund on dues paid for the year.

**Subscriptions on magazines and newspapers (that you no longer want):**

\_\_\_ Request a prorated refund on the subscription. \_\_\_\_\_

**NOTE:** A sample letter is included in the back of this booklet.  
Keep copies of all these letters.

**Church pledge:**

\_\_\_ If you feel that your family's church pledge for the current year is too large for you to pay, talk this over with your minister or the person who oversees the church finances. \_\_\_\_\_

**Social and Miscellaneous Tasks**

\_\_\_ Order a cemetery marker, if one is needed. (To order, look under "Monuments" in the yellow pages of the phone book.) \_\_\_\_\_

**NOTE:** The Veterans Administration provides cemetery markers for deceased veterans at no charge. If you desire one, call the local V.A. office.

If a family or spouse of the deceased is moving to a new address:

\_\_\_ 1. Arrange for the mail to be forwarded. \_\_\_\_\_

\_\_\_ 2. Discontinue utilities (including oil deliveries), newspapers, and telephone. \_\_\_\_\_

\_\_\_ Send cards and/or notes of acknowledgment for gifts, flowers, memorials, and kindnesses shown to the family. In some cases, phone calls may take the place of a written acknowledgment. Although all letters should be acknowledged, etiquette does not require acknowledgment of sympathy cards, visits, or attendance at the funeral. \_\_\_\_\_

\_\_\_ Return empty containers in which food was brought, if applicable. \_\_\_\_\_

\_\_\_ Write notes to out-of-town friends and other interested persons who may not be aware of the death. \_\_\_\_\_

\_\_\_ Dispose of the clothes and personal possessions of the deceased in the way and at the time that feel right for you. If there are items you don't want to pass on to friends and family members, charitable agencies would be glad to have most or all of them. Some of these agencies will come and collect them. \_\_\_\_\_

## **SPECIAL TASKS FOR YOUR FAMILY**

If there are any tasks your family needs to do that were not listed elsewhere, list them here:

### **!!!! Caution !!!!**

There are unscrupulous people who make a practice of reading obituary notices and preying on grieving families. Be wary of anyone you are not well acquainted with who:

- Offers you a deal too good to be true.
- Makes an unsolicited offer to sell your home, sell you insurance, or make home repairs.
- Claims to be a friend, relative, or business acquaintance of the deceased, and now asks a favor of you or claims that the deceased had promised (or owed) him/her money.
- Offers to increase the value of your insurance money by investing it for you.
- Expresses a romantic interest.

Before you sign anything or give money to anyone, consult your lawyer, banker, minister, or a knowledgeable relative or friend.

### **-- Finally --**

Take care of yourself and one another! Physical, as well as emotional problems are more common in those who have been under stress such as that caused by the prolonged illness and death of a loved one. In order to keep well, you need to:

1. Get plenty of rest.
2. Eat nutritious meals.
3. Dedicate some time to pampering yourself.
4. Find a friend, or several friends, with whom you can talk freely--or join a support group of some sort.
5. Find new interests and participate in activities that you enjoy.

If you feel you need special help, ask for it. Some possible resources are your doctor, minister, Hospice Volunteer, Hospice Bereavement, and local mental health agencies.

The death of a loved one is always associated with major and traumatic changes in the life of the surviving family members. If it is at all possible, avoid making any drastic life decisions, changes, or moves for at least a year. Remember that, for now, this day's needs are all you have to cope with. Be patient with yourself. Give yourself time to heal and wait for the future.

## **Sample Letter**

(Name & Address of Firm or Agency)

(Date)

Dear Sir or Madam:

This is to advise you that (full name of deceased), my (relationship to you), died on (date). Please cancel (his/her insurance, membership, subscription) and send me any (insurance, refund) to which (I am, the estate is) entitled.

Sincerely,

(Signature)

(Typed or Printed Name)

(Street Address, City, State, Zip Code)

NOTE: In letters regarding credit cards, change the second sentence to read:  
"The account number of \_\_\_\_\_. Please close this account."

Or

"Please remove my (relationship's) name and list the account only in the name of (your name)."