



*Patient and Family Guide  
To Hospice Care*



We are pleased to offer you this  
hospice booklet,  
which was made possible through the  
generous gifts of friends and families  
whose lives have been touched by the programs  
and services of FHN Hospice.

# *It is the hardest of all*

learning that the opposite of depression is not  
happiness—a radiant, receding goal—  
but vitality, to feel alive each minute  
you are given.



Then when sweetness comes it  
is most sweet, and when sorrow  
comes you know its name. In  
the aftermath of suffering, you  
chart each day as an explorer  
preceding map or compass,  
and what you find is shockingly alloyed. All happiness is  
dappled, and even bleakest tragedy has  
moments of strange praise.

—Nessa Rapoport

**FHN Hospice**  
**815-599-7240 • 24 Hours a Day**  
**Toll Free 877-873-3621**  
**Hospice Office Hours 8:00 a.m. to 5:00 p.m. Monday through Friday**

After business hours and on weekends when your regular nurse is not available, the after hours nurse has information about you and will help problem solve over the phone or make a home visit. When you call after hours, the answering service will take your information and have the after hours nurse return your call within 15 minutes. If for some reason you do not receive a call within 15 minutes, please call again.

Please keep the telephone line clear so that the nurse can reach you as quickly as possible.

**Reasons to call the after hours nurse:**

- Increased shortness of breath or painful breathing
- Increased pain or new onset of pain
- Uncontrolled nausea or vomiting
- Sudden, unexpected change of consciousness
- If you need to talk to the nurse about something that you feel cannot wait until regular business hours
- If you have run out of pain medications, or medication you use as needed, or you don't have enough to last the night
- If you are considering hospitalization, **please call us first** so we can help plan for your needs

**Please wait until the next working day—Monday through Friday, 8:00 a.m. to 5:00 p.m.—if:**

- You want to change the visit time of one of the Hospice Team (Chaplain, Social Worker, Home Health Aide, Volunteer, etc.)
- You want to know the time of the planned visit by your nurse or other team members
- You want to talk to your daytime nurse or social worker
- You are getting low on medications but it is not an emergency

**My Hospice Team Members:**

Nurse \_\_\_\_\_ Social Worker \_\_\_\_\_  
Home Health Aide \_\_\_\_\_ Chaplain \_\_\_\_\_  
Volunteer \_\_\_\_\_ Other \_\_\_\_\_

**Important Names and Numbers:**

Physician \_\_\_\_\_ Phone \_\_\_\_\_  
Physician \_\_\_\_\_ Phone \_\_\_\_\_  
Pharmacy \_\_\_\_\_ Phone \_\_\_\_\_  
Equipment Supplier \_\_\_\_\_ Phone \_\_\_\_\_  
Clergy \_\_\_\_\_ Phone \_\_\_\_\_

# Patient and Family Guide to Hospice Care

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# Introduction

This *Patient and Family Guide to Hospice Care* is designed to be a practical source of information about hospice care. It introduces you to the history and philosophy of the hospice movement. It describes the services most hospice programs offer. It gives you a profile of the various members of the interdisciplinary hospice team. It provides answers to many of the questions patients and their families have about caregiving, symptom management and pain control, and the grieving process.

Some caregivers find it helpful to write down messages and notes during the course of hospice care. Forms to help you do this are included. If you like, you may copy these pages so you won't run out of space.

Whether you are a patient, a primary caregiver, or a friend or family member (and by the way, we use "family" in the broadest, most inclusive sense of the word), we hope you will find this guide a valuable source of information, practical advice, and support. Keep it close by. Use it as your companion and organizing tool throughout your hospice care experience.

## Understanding Hospice Care

During the Middle Ages, the term "hospice" was used to signify a place where weary pilgrims could stop, rest, and refresh themselves before continuing on with their journey. In 1967, a British physician, Dr. Cicely Saunders, began using the term to symbolize a new kind of care for the dying. In a London suburb, she founded St. Christopher's Hospice which cared for their patients by offering supportive care and pain control. The patients at St. Christopher's came there because they had reached a point in their various illnesses where they were no longer looking for a cure. They wanted to make the most of the time left to them, to live out their lives at the highest level of quality possible, even if that compromised how long they would live.

Since its beginnings in 1967, the hospice movement has spread quickly throughout the world. In the United States alone, there are now over 1,500 hospice programs affiliated with the National Hospice Organization. These programs serve over 100,000 patients a year, and are recognized by patients, physicians, and insurance carriers as providing a high quality, cost-effective medical alternative for persons with limited life expectancies.

Today, hospice care still focuses on helping patients live out their lives at the highest level of quality possible. Hospice care does *not* support euthanasia or assist patients in expediting death in any way. While emergency nursing services are available 24/7, if needed, it does *not* provide 24/7 *live-in* service.

## What Services Does Hospice Care Include?

Hospice organizations vary greatly in size, but their philosophy and the services they offer remain largely the same. All hospices generally agree that basic hospice care should include the following elements:

- Care which focuses on the emotional, social, and spiritual needs of a dying person and that person's family, as well as on physical and medical needs;
- Care which is directed as much as possible by the patient, working together with the family and the hospice staff;
- Support and services provided by an interdisciplinary team composed of physician, nurses, social worker, counselors, therapists, chaplain, trained volunteers, and home health aides;
- Nursing care and support available for patients and primary caregivers on an on-call basis, 24 hours a day, 7 days a week

- Home-based care if possible; but if a patient's symptoms cannot be managed at home, then inpatient care provided in as pleasant and homelike atmosphere as possible, where family and friends are encouraged to be present. Hospice care often can be provided in area nursing homes;
- Bereavement support.

### ***Getting Started and Timing***

It is important for someone entering hospice care to have three things:

1. An understanding of their disease prognosis—that they have been diagnosed with a terminal illness, a prognosis of 6 months or less if it follows a normal course, and also an understanding of the kinds of services hospice does and does not provide;
2. The cooperation of their personal physician who is willing to work with the hospice team to provide care;
3. A family member or close friend who is willing to be the primary caregiver, if hospice care is to be provided at home.

All three of these elements are the key. The patient must understand and consent to the kind of care he or she will be receiving. The physician must be willing to support this kind of care. Hospice will require that there be a primary caregiver when patient is unsafe to be left alone.

*To get the most out of hospice care it is important that it begin neither too early, nor too late. Too early is when a patient is still seeking a cure. Too late is when death is very near and there is little or no time left for hospice care to make a contribution to quality of life for patient and family.*

### **The Family's Role in Hospice Care**

Even fifty years ago, it was common for people to die at home, surrounded by loved and familiar faces and possessions. Now, most people die in hospitals or other institutions, surrounded by tubes and monitors and other technological equipment. Hospice care seeks to take death out of this institutional setting and relocate it to an environment where the patient is most comfortable.

The families who have been supported by a hospice program in caring for their dying loved ones almost universally consider it a positive, empowering experience. Hospice team members are trained to be sensitive to the needs of patient *and* family. If your mother wants to die at home, and you wish to support her in this, but are worried whether you can provide the care she needs, hospice will give both training and emotional support. Hospice programs also offer the option of respite care. Respite care is having a volunteer care for your loved one for a few hours so that you can have a break. It provides much needed time for rest and renewal. Sometimes, caring for a dying friend or relative seems an overwhelming task; hospice care works to make it manageable.

Some people worry about having someone who is dying in the home if children are present. They are afraid it will be a negative or frightening experience for the children. You need to assess your own child's or children's needs and strengths, and their relationship with the person who needs care. However, it is helpful to know that for many families with children, taking care of a dying family member at home turns out to be a source of great family strength and positive energy. Your children, like you, will need education and support for this to be a good experience, but with the needed support, it can be a rare time of closeness and caring for them and can teach them much about life and family values.

Clearly, if your friend or relative makes a choice for hospice care, and you are involved as a primary caregiver, the experience will have a significant impact on your life. It will be both physically and emotionally draining. However, it can also be deeply satisfying for you both. If you might be involved in a caregiving role in a hospice setting, you should feel free to talk with hospice personnel yourself. Find out what the expectations are of you and exactly what kind of help is available. Talk with persons who have cared for a parent or other relative or friend with hospice support and see how they experienced that relationship. It is a major commitment. Take time to make a good decision for yourself.

Hospice care is not for everyone. However, for those who choose it, it can provide compassionate, sustaining care for the dying and their families. It is an option well worth considering.

## Paying For Hospice Care

*If you have Medicare Part A or Medicaid coverage, you may be eligible for the Medicare or Medicaid Hospice Benefit. A Hospice staff person will help you determine your eligibility. If you elect the Medicare (or Medicaid, if available) Hospice Benefit the following will be covered:*

- Intermittent home visits by the Hospice staff
- Medications
- Supplies
- Medical Equipment
- Short-term inpatient respite
- Lab tests
- Outpatient procedures to alleviate symptoms
- Hospitalizations for symptom management

*As long as these items or services are:*

- Related to your terminal illness;
- Authorized by your Hospice provider as palliative and part of your Hospice plan of care; and
- Obtained through a contracting provider approved under the program.

Office visits to see your primary physician will be covered in the same way as before you elected the Medicare or Medicaid Hospice Benefit.

*If you access care without consulting your Hospice team, neither Hospice nor Medicare/Medicaid will be responsible for the charges associated with the care you obtain.*

*If you decide to change your approach to treatment from a comfort-oriented one to a more aggressive or curative approach, you may revoke the Medicare or Medicaid Hospice Benefit and your regular Medicare/Medicaid benefits will be resumed.*

*If you have private insurance, Hospice will clarify whether you have hospice coverage and its scope.*

*If you have two insurance policies, please inform your hospice team, so they can work to coordinate and maximize your coverage.*

*If you have limited or no coverage for hospice services, Hospice staff will work with you to determine your potential eligibility for Financial Aid.*



# The Hospice Team

## Nurses

Often, the first person you will meet from the hospice team is a nurse. During this visit the nurse will explain the hospice philosophy and services. The nurse will work with you to determine which hospice team members will visit you and your family. The nurse's primary goal is to provide symptom management and comfort.

### **The hospice nurse will:**

- Assess your comfort and any symptoms which may need attention, such as pain, nausea, etc.;
- Work in coordination with your physician to manage symptoms;
- Perform procedures such as placing and maintaining catheters, wound care, blood draws, etc.;
- Teach the caregiver the proper use of catheters, routine dressing changes, medication;
- Suggest and help in obtaining needed equipment and services;
- Discuss the effects of illness and treatment;
- Listen to your concerns and offer support.



## Social Workers

Hospice social workers work closely with patients and their families to create and maintain a supportive in-home care system to ensure the patient's safety and comfort, and to address the special needs of caregivers.

Hospice social workers are available to help patients and their families address the many personal, financial, emotional and care planning issues that arise.

### **The hospice social worker is able to:**

- Identify community resources and help with referrals to them;
- Determine eligibility for state and local assistance programs;
- Clarify insurance coverage and answer questions regarding financial concerns;
- Help patients and families arrange for added care giving support at home or in an alternative care setting;
- Provide information concerning advance directives, such as a health care directive (living will) and appointment of a health care representative or proxy;
- Assist in funeral and memorial planning;
- Listen to your concerns and provide emotional support.

Social work visits vary in frequency and length depending on the needs of patients and their families. A social worker will usually contact you by telephone within one week of admission to schedule an initial appointment.

## Chaplain

The Hospice Chaplain is available to help with spiritual concerns which may arise. Sometimes a listening ear or a thoughtful reading can help you find meaning in the midst of a difficult time. The chaplain uses a nondenominational approach and can also help connect you with various religious organizations. The chaplain does not replace your minister, rabbi, or priest.

We believe that your mental and spiritual well-being is as important as your medical condition. The chaplain is specially trained to help you and your family with spiritual issues or concerns arising from terminal illness. The chaplain is available as needed.

### **The hospice chaplain:**

- Is available to meet with you and/or your family to share hopes, fears, dreams and concerns, whether spiritual or otherwise;
- Will support you in your exploration or struggles with spiritual and/or emotional issues;
- Can provide spiritual counseling, respecting your personal beliefs;
- Will not impose any particular religious orientation;
- Will pray with you if requested;
- May be available to assist you in planning a funeral, memorial service, or other observance you wish to have conducted;
- Can help obtain clergy services from the denomination of your choice;
- Can teach relaxation techniques to help achieve greater peace.

### **Therapy Services**

Physical, Occupational, and Speech Therapists are available to assist in promoting the independence, quality of life, and safety of the patient and family. Your hospice nurse can help determine if a referral to one of these therapists might be helpful.

#### **The Therapist may:**

- Evaluate the medical equipment needs;
- Provide or assist in arranging for equipment as needed, such as hand held showers, bath seats, walkers and canes;
- Train family and caregivers in proper use of equipment;
- Identify safety hazards;
- Help the patient maximize their strength and mobility through the use of equipment and exercise programs;
- Evaluate leisure interests and teach skills and activities that improve quality of life;
- Teach transfer skills and energy-saving techniques to maintain safety for the patient and caregivers;
- Teach family and caregivers exercises for the bed bound patient that may relieve pain and discomfort caused by lack of mobility;
- Evaluate communication or swallowing difficulties and recommend ways of handling these.

### **Home Health Aides**

Home Health Aides are certified nursing assistants. They provide personal care needs. They may visit two or three times per week, depending on the situation. The home health aides work closely with the nurses and other hospice team members providing some assistance with personal care needs. Some of the services they provide include:

- Bathing the patient and changing bed linens
- Shampooing, grooming and shaving
- Wound care
- Skin care
- Assistance with toileting
- Light homemaker services

### **Hospice Volunteer Program**

The Volunteer Coordinator works closely with all team members, especially nurses and social workers to determine how a volunteer and the various services they offer may benefit both the patients and caregivers. The coordinator will contact you, verify your requests, and introduce the volunteer to you.

The Hospice Volunteer is an important member of the hospice care team and performs duties which supplement, but do not substitute for, professional services. The volunteer can provide an empathetic, non-judgmental, listening and caring presence for both patients and their caregivers.

Volunteers are individuals from a variety of backgrounds who provide an important part of our service. Volunteers have been specially selected and receive in-depth training before they are assigned to a patient and family.

**Volunteers can:**

- Stay with the patient so the family can rest;
- Read and listen to patients, and be a good companion;
- Run errands, do grocery shopping, and pick up prescriptions;
- Do light housework or laundry, or prepare meals;
- Take children or grandchildren for an outing;
- Or ... let us know how we may help you.

The admission nurse or social worker may discuss the volunteer program with you. A referral can then be made for volunteer services. The Volunteer Coordinator will contact the patient or family to clarify specific needs and answer questions concerning volunteers and/or the program. You may also request volunteer services from any hospice team member making a home visit. Patient and family needs change, and a request for a volunteer may be made at any time. You may also call the office directly, and speak with the Volunteer Coordinator to make a request or for further information.

A volunteer may not give a patient his or her medications without it first being pre-measured out of the bottle or box. If you will not be home at the time the medication is due to be given, be sure to have the medications measured out with clear instructions on when it should be handed to the patient.

**Pharmacist**

Hospice uses pharmacy support when providing care. Questions regarding medications or prescriptions should be directed to your nurse. He/she will contact the pharmacist and respond to your questions and needs as quickly as possible.

**Bereavement – Grief Support Services**

Hospice is committed to serve and provide support for family and friends, both before and after the death of the patient. A bereavement program...or grief support services...is an important aspect of this commitment. The program provides a variety of services to the family to help cope with grief and loss after the death of a loved one.

**Bereavement support may include:**

- Short term counseling for individuals, couples or families;
- Supportive grief seminar/support group;
- Referral to other community resources available in your area;
- Follow-up after the death of your loved ones;
- Information on coping with grief and loss;
- Subscription to bereavement pamphlet "Journeys" for one year.

# STATEMENT OF ILLINOIS LAW ON ADVANCE DIRECTIVES AND DNR ORDERS

Last updated July 19, 2002

You have the right to make decisions about the healthcare you get now and in the future. An advance directive is a written statement you prepare about how you want your medical decisions to be made in the future, if you are no longer able to make them for yourself. A do not resuscitate order (DNR order) is a medical treatment order that says cardiopulmonary resuscitation (CPR) will not be used if your heart or breathing stops.

Federal law requires that you be told of your right to make an advance directive when you are admitted to a healthcare facility. Illinois law allows for the following three types of advance directives: (1) healthcare power of attorney; (2) living will; and (3) mental health treatment preference declaration. In addition, you can ask your physician to work with you to prepare a DNR order. You may choose to discuss with your doctor different types of advance directives and DNR orders. After reviewing information regarding advance directives and DNR orders you may decide to make more than one. For example, you could make a healthcare power of attorney and a living will.

If you make one or more advance directives and/or a DNR order, tell your doctor and other healthcare providers and provide them with a copy. You may also want to provide a copy to family members, and to those you appoint to make these decisions for you.

State law provides copies of sample advance directives forms and DNR order forms.

## Healthcare Power of Attorney

The **healthcare power of attorney** lets you choose someone to make healthcare decisions for you in the future, if you are no longer able to make these decisions for yourself. You are called the “principal” in the power of attorney form and the person you choose to make decisions is called your “agent.” Your agent would make healthcare decisions for you if you were no longer able to make these decisions for yourself. So long as you are able to make these decisions, you will have the power to do so. You may use a standard healthcare power of attorney form or write your own. You may give your agent specific directions about the healthcare you do or do not want.

The agent you choose cannot be your doctor or other healthcare provider. You should have someone who is not your agent witness your signing of the power of attorney.

The power of your agent to make healthcare decisions on your behalf is broad. Your agent would be required to follow any specific instructions you give regarding care you want provided or withheld. For example, you can say whether you want all life-sustaining treatments provided in all events; whether and when you want life-sustaining treatment ended; instructions regarding refusal of certain types of treatments on religious or other personal grounds; and instructions regarding anatomical gifts and disposal of remains. Unless you include time limits, the healthcare power of attorney will continue in effect from the time it is signed until your death. You can cancel power of attorney at any time, either by telling someone or by canceling it in writing. You can name a backup agent to act if the first one cannot or will not take action. If you want to change your power of attorney, you must do so in writing.

## Living Will

A **living will** tells your doctor whether you want death-delaying procedures used if you have a terminal condition and are unable to state your wishes. A living will, unlike a healthcare power of attorney, only applies if you have a terminal condition. A terminal condition means an incurable and irreversible condition such that death is imminent and the application of any death delaying procedures serves only to prolong the dying process.

Even if you sign a living will, food and water cannot be withdrawn if it would be the only cause of death. Also, if you are pregnant and doctors think you could have a live birth, your living will cannot go into effect.

You can use a standard living will form or write your own. You may write specific directions about the death-delaying procedures you do or do not want.

Two people must witness your signing of the living will. Your doctor cannot be a witness. It is your responsibility to tell your doctor if you have a living will if you are able to do so. You can cancel your living will at any time, either by telling someone or by canceling it in writing.

If you have both a healthcare power of attorney and a living will, the agent you name in your power of attorney will make your healthcare decisions unless he or she is unavailable.

### **Mental Health Treatment Preference Declaration**

A **mental health treatment preference declaration** lets you say if you want to receive electroconvulsive treatment (ECT) or psychotropic medicine when you have a mental illness and are unable to make these decisions for yourself. It also allows you to say whether you wish to be admitted to a mental health facility for up to 17 days of treatment.

You can write your wishes and/or choose someone to make your mental health decisions for you. In the declaration, you are called the “principal” and the person you choose is called an “attorney-in-fact.” Neither your doctor nor any employee of a healthcare facility in which you reside may be your attorney-in-fact. Your attorney-in-fact must accept the appointment in writing before he or she can start making decisions regarding your mental health treatment. The attorney-in-fact must make decisions consistent with any desires you express in your declaration unless a court orders differently or an emergency threatens your life or health.

Your mental health treatment preference declaration expires three years from the date you sign it. Two people must witness you signing the declaration. The following people may not witness your signing of the declaration: your doctor; an employee of a health care facility in which you reside; or a family member related by blood, marriage or adoption. You may cancel your declaration in writing prior to its expiration as long as you are not receiving mental health treatment at the time of cancellation. If you are receiving mental health treatment, your declaration will not expire and you may not cancel it until the treatment is successfully completed.

### **Do-Not-Resuscitate Order**

You may also ask your health-care professional about a **do-not-resuscitate order** (DNR order). A DNR order is a medical treatment order stating that cardiopulmonary resuscitation (CPR) will not be attempted if your heart and/or breathing stops. The law authorizing the development of the form specifies that an individual (or his or her authorized legal representative) may execute the IDPH Uniform DNR Advance Directive directing that resuscitation efforts shall not be attempted. Therefore, a DNR order completed on the IDPH Uniform DNR Advance Directive contains an advance directive made by an individual (or legal representative), and also contains a physician’s order that requires a physician’s signature.

Before a DNR order may be entered into your medical record, either you or another person (your legal guardian, health care power of attorney or surrogate decision maker) must consent to the DNR order. This consent must be witnessed by two people who are 18 years or older. If a DNR order is entered into your medical record, appropriate medical treatment other than CPR will be given to you. A copy of the Illinois Department of Public Health (IDPH) Uniform Do Not Resuscitate (DNR) Advance Directive that may be used by you and your physician can be found at <http://www.idph.state.il.us/public/books/advdir4.htm>. This webpage also provides a link to guidance for individuals, health-care professionals and health-care providers concerning the IDPH Uniform DNR Advance Directive.

## What happens if you don't have an advance directive?

Under Illinois law, a healthcare “surrogate” may be chosen for you if you cannot make healthcare decisions for yourself and do not have an advance directive. A healthcare surrogate will be one of the following persons (in order of priority): guardian of the person, spouse, any adult child(ren), either parent, any adult brother or sister, any adult grandchild(ren), a close friend, or guardian of the estate.

The surrogate can make all healthcare decisions for you, with certain exceptions. A healthcare surrogate cannot tell your doctor to withdraw or withhold life-sustaining treatment unless you have a “qualifying condition,” which is a terminal condition, permanent unconsciousness, or an incurable or irreversible condition. A “terminal condition” is an incurable or irreversible injury for which there is no reasonable prospect of cure or recovery, death is imminent and life-sustaining treatment will only prolong the dying process. “Permanent unconsciousness” means a condition that, to a high degree of medical certainty, will last permanently, without improvement; there is no thought, purposeful social interaction or sensory awareness present; and providing life-sustaining treatment will only have minimal medical benefit. An “incurable or irreversible condition” means an illness or injury for which there is no reasonable prospect for cure or recovery, that ultimately will cause the patient’s death, that imposes severe pain or an inhumane burden on the patient and for which life-sustaining treatment will have minimal medical benefit.

Two doctors must certify that you cannot make decisions and have a qualifying condition in order to withdraw or withhold life-sustaining treatment. If your healthcare surrogate decision maker decides to withdraw or withhold life-sustaining treatment, this decision must be witnessed by a person who is 18 years or older. A healthcare surrogate may consent to a DNR order, however, this consent must be witnessed by two individuals 18 years or older.

A healthcare surrogate, other than a court-appointed guardian, cannot consent to certain mental health treatments, including treatment by electroconvulsive therapy (ECT), psychotropic medication or admission to a mental health facility. A healthcare surrogate can petition a court to allow these mental health services.

*“That which was bitter  
to endure may be  
sweet to remember.”*  
—A Proverb



# Symptom Control In Hospice Care

## Pain

Fear of pain is common for patients and their families. It is important to listen to patients when they say they are experiencing pain. For patients, pain may be both a physical and an emotional experience. Only the patient can best describe the pain and its intensity. There are many ways to manage pain effectively. The hospice team will work with you to provide good symptom control.

The nurse and doctor need a clear understanding of your pain level, the type of pain, and how well medications are controlling it.

How much pain do you have? You can use a scale of 0 to 10 to describe how much pain you have. "0" means no pain at all; "10" means the most pain you've ever experienced. You may be asked to rate your pain, using this scale, when you are resting and when you are active.

0—1—2—3—4—5—6—7—8—9—10

How do you describe the type of pain you have? Here are some words people use to describe the pain they are experiencing. You may choose to use other words. Use the words that best fit your experience.

**Sharp—shooting—aching—stabbing—pulsing—crushing—tingling—dull cramping  
itching—burning—cutting—throbbing**

The type of pain is as important as its intensity in determining the best medications for you. Other medications may be prescribed, in addition to your regular pain medication, to better control your type of pain. These additional medications may be more familiar to you as treatment for other problems, such as depression, muscle tension, anxiety, or inflammation.

On pages 39 and 40 of this Guide there are medication sheets. They can be used to note medications taken regularly and those taken "as needed."

Frequent concerns about pain medications are:

*"The pain medication makes me too sleepy."*

Some pain medications can make you feel drowsy. This sleepiness usually goes away after a few days. If you have lost sleep because of pain, you may sleep more the first few days after beginning your new medication, because your body is finally relaxing. The medications can be adjusted to decrease sleepiness but maintain comfort.

*"The pain medicine makes me constipated."*

Constipation is a common side effect of many pain medications. Other factors may also be contributing to constipation, such as decreased activity, decreased appetite, or a disease process. Constipation may be treated or prevented by balancing the effects of medications and decreased appetite and activity with stool softeners and laxatives.

*"If I take pain medicine now, what will I do if the pain gets really bad?"*

Pain does not always get worse. Experience shows that medication dosages may be increased, or the medication changed, to continue to provide pain management throughout the course of your illness.

*"Will I become addicted?"*

Drug addicts want and need drugs to get "high." This is different than requiring medications to treat pain.

You may have other questions about pain medications: how, why, or when to take them. Ask your nurse questions as you think of them.

By taking medications regularly, it may be possible to minimize the need to take additional medications. Chronic pain is more easily managed with fewer medications when pain is kept at low levels and is prevented by taking medications regularly.

Pain may contribute to other problems, such as nausea and vomiting, irritability, confusion, loss of sleep, and immobility. Most people have a better quality of life when they are pain free or experiencing low levels of discomfort.

Pain and discomfort can also be managed by other methods. Meditation, music, or guided imagery can allow your mind to relax and reduce the pain. Use of cool or warm packs, or changing position may also assist in soothing aches. Massage may help to decrease discomfort by increasing circulation and relaxing muscles. Your hospice team may be able to assist you with these techniques or direct you to other resources.

### **Taking Your Medication Safely**

- Take only medication **PRESCRIBED** for you;
- If you are unsure of how to take your medication contact your nurse;
- **ALWAYS** take your medication as directed;
- Tell your nurse if you are having difficulty taking your medication, such as swallowing difficulty;
- Space the times you take your medicines as evenly as possible;  
Once-a-day: Take once each day at the same time everyday.  
Two-times-a-day: Take once in the morning, once in the evening.  
Three-times-a-day: Take once in the morning, once in the afternoon, and once in the evening.  
Before meals: Take ½ hour before you eat.
- Many pain medications are ordered as needed, or so many hours. It is **IMPORTANT** to **AVOID** allowing pain to become intense before “Taking” the next dose;
- Take your regularly scheduled pain medication even if your pain is controlled;
- If you are having pain you will not become addicted to the medication. You may build a tolerance and the medication frequency or dosage may need adjusting. A different medication may be needed;
- Any medication may produce unwanted side effects. Tell your nurse of new symptoms or concerns you think may be related to your medication;
- Be sure to tell your nurse of any **ALLERGIES**.

### **Dizziness**

Dizziness is a symptom that may occur from several different causes. Following are a few suggestions to assist with this symptom. Safety is the primary concern.

- Rise out of the chair or the bed slowly, allowing your feet to dangle at the side of the bed first. Frequently, dizziness will go away after 1-2 minutes;
- Change positions slowly and use a cane or walker if available;
- Maintain a safe environment. Keep objects out of the area where you will be walking. Ask for assistance if you feel unsteady;
- If you are dizzy, drowsy, or very tired, avoid activities like driving, cooking, or handling machinery;
- If tolerated, increase fluids. Drinking things such as Gatorade® or Pedialyte® can be especially helpful.

### **Nausea and Vomiting**

Sometimes patients experience nausea and vomiting. The following suggestions may help:



- Eat small, frequent meals;
- Avoid liquids at mealtime—drink them an hour after meals;
- Eat dry foods such as toast and crackers;
- Avoid spicy, fried, and fatty food, red meat and food with a strong odor;
- Pay close attention to mouth care;
- Take anti-nausea medication when prescribed (regularly or prior to meals);
- Unless instructed not to, take medications with small amounts of food or milk;
- Serve food cold or at room temperature to decrease its smell and taste;
- The nausea caused by pain medication can feel like motion sickness. If this happens, try resting quietly. If you suspect your pain medicines are making you sick, tell your nurse.

## Constipation

When people are very ill, many things can affect how their bowels function. Change in diet, activity, and the use of some medications can produce constipation. This is because the narcotic in the pain medicine slows down the bowel, allowing too much water to be absorbed from the waste matter. The result is a sluggish bowel with hard, dry stool.

Treatment is aimed at speeding up (stimulating) the bowel and/or putting more water into the stool. The medicines often prescribed are supposed to prevent constipation. It is important that you take them routinely as directed by your doctor or nurse. You can also increase fluid intake and activity, as tolerated, to help decrease constipation.

### Bowel problems to report to the nurse:

- Very hard, difficult to pass stool;
- More than three days without a bowel movement;
- Constipation followed by diarrhea;
- Constantly passing only smears of stool or liquid stool;
- Blood with the stool;
- Abdominal pain.

Your nurse may advise you to use the following fruit paste recipe:

#### Anti-constipation Fruit Paste

*(Dose: 1-2 tablespoons per day)*

¼ pound prunes	¼ cup brown sugar
1 ounce senna tea*	¼ pound figs
¼ pound raisins or pitted dates	¼ cup lemon juice

*Prepare the tea using ¾ cup boiling water. Steep for 5 minutes. Strain the tea and pour ½ cup into a large pot. Add fruit and boil for 5 minutes. Remove from heat, add sugar and lemon juice. Allow mixture to cool. Use hand mixer, food processor, or blender, turn fruit mixture into a smooth paste. Spoon into jar or airtight container and place in freezer. Note: the fruit paste does not freeze solid but keeps indefinitely in the freezer.*

*Serving ideas—on toast, on hot cereal, in ice cream, yogurt, etc.*

*\*Senna tea can be found in health food stores, grocery stores, and pharmacies.*

## **Dry or Sore Mouth**

Good mouth care is very important. Decreased fluid intake, some medications, or physical conditions can leave your mouth dry and/or sore. The following are suggestions to ease some of the discomfort of a dry and sore mouth.

### **Dry Mouth**

Avoid smoking, drinking alcohol, and eating spicy foods. Try Popsicles, shakes, yogurt, pineapple chunks, gum, or hard candy such as lemon drops.

- Drink plenty of fluids;
- Rinse your mouth frequently;
- Take good care of your teeth and gums by flossing and brushing regularly. Using a soft tooth brush may be helpful if your mouth is sore;
- The nurse may also have “toothettes” which are sponges on a stick. They can be used with water to moisten the mouth and for general mouth care. Avoid the use of lemon glycerin swabs because they dry people’s mouths.

### **Sore Mouth**

- Avoid acidic foods like orange juice, tomato juice, and citrus fruit;
- Use a straw to prevent liquids from coming in contact with sores;
- If dentures are too loose, have them adjusted and remove them while sores on the gums are healing;
- Some people get white patches of yeast in their mouths. If this happens, the nurse will seek to obtain medications to ease the discomfort.

## **Food and Eating**

It is common for people to lose their appetite when ill. This may be from the disease itself, treatments, medications, pain, or simply changes in the way food tastes. The body’s need for calories and protein-rich foods is altered because of decreases in activity, exercise, and general metabolism.

### **Suggestions for eating when appetite is diminished:**

- Eat frequent, small meals;
- Drink liquid breakfast drinks, canned supplements such as Ensure, or homemade high-calorie shakes;
- Add dried milk or dried protein powder to liquid or soft foods to add calories;
- Drink fruit juices, such as prune or apricot nectars, to provide additional calories;
- Eat and drink favorite foods;
- Give liquids in other forms, such as Jell-O, pudding, Popsicles and ice cream;
- Avoid using straws, which may increase the swallowing of air, leading to burping or nausea;
- Refer to the instructions on dietary supplements for storage, use, and expiration date.

When our bodies are able to heal, we need proper nutrition to regain strength. However, when our bodies are not able to heal (often the last weeks of life) food can become an unnecessary burden and a source of discomfort. A decreased appetite can create anxiety and tension for both the patient and caregiver. Attempting to force oneself to eat may drain precious energy and lead to nausea and vomiting at a time when the body is saying “no” to food or fluids. Loss of appetite and diminished fluid intake is a part of normal dying. As a caregiver, providing nourishment to the patient may feel like “the only thing left I can do.” Speaking with the hospice nurses, and sharing your feelings with the patient, may help you through this uncomfortable issue.

## **Skin Problems**

Superficial skin sores, pressure sores or bed sores affect some people. They are caused primarily by a decrease in skin health and extended time in bed or a chair. Prevention is the best cure for skin problems.

### **Here are a few tips on how to avoid bed sores:**

- Change positions in bed by turning from side to side every four hours;
- If able, get out of bed and sit in a chair;
- Gently rub the skin with lotion to increase circulation;
- Keep skin clean and dry;
- Change soiled or wet linens and clothing as needed to keep patient dry;
- Clean the skin regularly of any drainage, blood or urine;
- Use pillows to support the leg and back when lying on your side;
- Use a special mattress on the bed, such as an egg crate foam pad, sheepskin, or air mattress;
- Apply protective pads to bony areas like the heels, elbows, and tailbone as recommended by your nurse.

The hospice team may have other suggestions depending on your situation. If you notice any redness, sores or bruises on the patient, communicate this to your nurse.

## **Emotional Withdrawal**

It is common for the terminally ill to begin withdrawal from their familiar activities, such as work, hobbies, relationships, and so on. The need to communicate with others may be lost. Words may lose their importance. Touch and silently being with the patient may become more meaningful. Withdrawal is often used by patients to conserve energy and for self-reflection. Life review may become an important task. The hospice staff is available to assist in this life review process with patients, friends, and families. You should discuss with hospice staff your questions and concerns about signs of your loved one’s emotional withdrawal.

## **Disorientation/Symbolic Language**

One or two weeks prior to death, the patient may begin to sleep most of the time. It becomes difficult for the patient to keep their eyes open. They may become disoriented to time and place. Patients often become confused, talk or gesture to people who are not present or those who have already died. They may speak in what is often referred to as Symbolic Language.

This may include statements like “*I’ve got to pack for my trip,*” or “*I’ve got to cross the bridge now.*” These activities are normal and can be reassuring and calming for the patient.

If you have questions or concerns, speak with the hospice staff.

# Information And Skills For Caregivers

*Rule No. 1: Don't Forget to Take Good Care of Yourself*

## **Taking Good Care of Yourself**

Caregivers also need to receive care. Your emotional and physical well-being are very important and often difficult to maintain. Small things you do for yourself can make a *big difference*. It is important that those in the role of caregiver care for themselves. This will allow the best care to be provided to your loved one.

*Some suggestions are:*

- **Accept help**

Friends, family, hospice volunteers, and hired assistants can be a great source of support. Accepting this help is a good way to involve those people, as well as a way to take a necessary break yourself. In accepting help, it is best if you can be specific about your needs. Ask someone to run errands, do yard work, bring food, sit with the patient while you go for a walk or take a nap.

- **Take time for yourself**

A few quiet moments can be renewing. A walk with a friend can help you reestablish your perspective. A bath, while someone else cares for the patient, can ease the aches of body and soul. It is important to make time for yourself and identify pleasurable activities as a part of the care giving routine. Try to set a goal of at least one outing per week. This kind of personal time allows you to focus on other aspects of life.

- **Pay attention to your own physical needs**

You may become so busy being a caregiver that you forget about your own needs. Eating, sleeping, and exercising can make a big difference in your outlook. Healthy frozen dinners, meals prepared by a friend, a nap to offset missed sleep, and/or a short walk around the block can really help.

- **Practice relaxation techniques**

Pause for five minutes and breathe deeply. Count breaths or focus on pleasant images while sitting in a relaxed state in a quiet place. Try this especially when someone else is providing the patient's care (like when a hospice team member stops by). Don't forget that laughter and keeping your sense of humor are important, too.

## **Care for Someone in Bed**

As people become weaker, they stay in bed and/or chairs longer. Changing position is important. Often, as people become weaker they do not move easily on their own. Moving and changing positions can ease some of the discomfort that may occur. Changing positions every 2-4 hours prevents pressure sores and stiffness. The changes can be only a small amount and yet relieve the pressure. Ask the nurse about using an egg crate and/or air mattress.

*When caring for someone in bed, the following can be helpful to simplify the process:*

- Explain what you are doing. The more someone knows what you are doing, the more they can cooperate and let you know how they would like to be turned;
- Provide pain medication prior to movement, if uncomfortable;
- Two people can move someone easier than one;
- Keep any tubing free from being blocked off or pulled on.

## **Body Mechanics (Back Safety)**

- Avoid twisting your back or trunk; use your legs and feet to turn in place;
- Lift with your legs, not your back;
- Bend or flex knees; use legs and stomach muscles.

## **Use of “Pull/Roll Sheet”**

A folded sheet (“pull/roll sheet”) placed under the body (neck to buttocks) can be used to move the patient around in the bed. It assists to maintain the body alignment during movement.

- Always support head if person is unable to;
- Two people can move a person up in the bed by rolling the sides of the sheet up and close to the person’s hips and together moving the person up in bed;
- One person can use sheet to move a person over to one side of the bed and/or to roll them on their side.

## **Other Hints in Adjusting Position**

- When moving the patient to the near side of the bed, begin with the head then the shoulders, trunk, legs, and feet;
- When moving from side to side, it can be helpful to bend and flex the knee. This helps the rotation of the hip; the body will follow;
- When the person is in the new position, support the arms and legs with pillows or rolled up towels, especially when the person is in a side-lying position;
- If the person is unable to communicate, imagine yourself in that position. Check that the person is not lying on the shoulder and/or arm;
- Rearrange pillows. Pillows can be placed for support under the person’s head, between the knees, or under hands or arms;
- Keep skin clean and dry. Keep linen and clothing dry and wrinkle free;
- Reddened areas or opened areas of skin need to be checked by the nurse;
- Apply lotion and massage the skin to assist in increasing the circulation and general comfort.

## **Transferring (Moving from One Place to Another)**

Plan ahead what you are going to do and the easiest way to do it.

### **When moving someone from bed to a chair:**

- Place the bed in a low position;
- Always assist patient to their strong side if they have one;
- Always lock/secure the bed, the wheelchair, and/or chair to prevent movement. Place the chair close to the bed, equalizing heights as much as possible;
- If moving from the bed to chair, put the bed in its lowest position with the head raised to a sitting position, if possible;
- Stand in front of the person being transferred;
- Stand with your feet apart. This position broadens your base support, improving your balance and control when moving;
- Help the person to a sitting position;
- Give the person time in a sitting position to be sure that any dizziness subsides before attempting to get them up;
- Absorb the strain with your knees and legs, not your back. Keep your back straight;
- Flex your hips slightly;
- Stand in front of the person and put your arms around their body, placing your hands on their ribs in back;
- Instruct the person to place their hands on your shoulders, not around your neck;
- Make sure the person who is being moved has his or her feet on the ground;
- Using your weight to balance, and keeping your knees slightly bent, gently rock the person into a standing position;

- To turn, continue to counterbalance with your weight and maintain a wide-based stance. Pivot on your feet, slowly turning your whole body, not twisting your trunk;
- Gently lower the person into the chair by bending your knees.

### **Providing a Bath While in Bed**

Bathing a person provides for more than cleanliness. Baths encourage exercise, stimulate circulation, prevent pressure sores, promote relaxation, and give you an opportunity to look at the skin for open areas.

#### **Assemble Supplies:**

- towels
- washcloth
- clean clothes
- soap (oatmeal soap can help with itching)
- basin
- lotion (containing lanolin)

#### **General Principles:**

- When giving a bath, encourage independence when possible;
- Give pain medications one hour before bathing, if movement is painful;
- Provide privacy and prevent drafts;
- Suggest toileting before beginning;
- Adjust the bed to a comfortable position;
- Bathe only a small area at a time to avoid chills;
- Dry the person as you bathe;
- Change the water frequently when it is dirty, soapy, or cool;
- If the person is unable to tolerate a full bath, offer to wash the face, hands, back and perineal area only;
- Avoid powders. Cornstarch is a good substitute for powder and can be lightly sprinkled on linen.

#### **Process for Bathing:**

- Fill basin two-thirds full with warm water;
- Wash one area at a time, starting with the face;
- Wash the eyes from the inner to the outer corner using water only; rinse the cloth after each eye;
- Wash and rinse the face, neck, and ears;
- Work from the head down, washing with long, circular motions, washing, rinsing, and drying thoroughly;
- The person may want to clean the perineal area themselves, but if they are unable to— for females, separate the labia with one hand and cleanse the area with downward strokes. For males, clean the penis with circular motions. Pull back the foreskin of the uncircumcised male to clean this area. Wipe from front to back, changing location with each wipe. Daily washing of this area and after toileting is important to prevent infection and skin breakdown. There are skin-protecting lotions that can be applied;
- Roll the person to the side;
- Wash, rinse, and dry the backside;
- Wash feet. Sometimes it's comforting to place feet in a basin of water;
- Apply deodorant, lotion and put on clean clothes, gown, or pajamas.

## Mouth Care

Remember to assist with mouth care, as needed. Often, this is easily forgotten. Cleaning the mouth helps prevent sores and may improve appetite.

### Assemble Supplies:

- soft toothbrush or toothette
- towel
- toothpaste
- small bowl

### General Principles:

*When providing for mouth care, have the person sit up in an upright position, if possible.*

- Place the towel under his or her chin;
- Brush teeth and gums gently with toothpaste;
- Try to remove all food particles and crusted materials;
- Avoid putting toothbrush too near the back of the person's throat, as this may cause the person to gag;
- Rinse the mouth out with cool water;
- If the person has dentures, remove and clean them. Cleaning after meals is also helpful. When people lose weight, dentures may no longer fit properly. This may be caused by a change in the shape of the jaw. Poorly fitting dentures may result in mouth sores. Some people choose to leave dentures out and eat softer foods;
- If you notice mouth sores, tell the nurse. There are medications that can provide comfort;
- After completing mouth care, apply a moisturizer to the lips and the corners of the mouth to prevent cracking.

## Changing Linens

Clean sheets can be helpful to make an individual feel more comfortable. Change sheets whenever they're dirty, wet, or sweaty. This might mean changing sheets anywhere from several times a day to once a week. This is easier if the person can get out of bed, but if that is too difficult, the following are brief instructions:

- Have the clean linens available and near before you begin;
- Untuck the top sheets;
- Move the person to one side of the bed. If the bed has a side rail put it up. Roll the person onto their side facing the side rail. Be careful the person doesn't slip off the side;
- Loosen the bottom sheets along the other side of the bed and roll them up along the person's back;
- Position the clean bottom sheet on the open side of the bed and tuck it in;
- Fold the remainder of the clean sheet and roll it close to the dirty sheet;
- Help the person roll over both sheets to the area of the clean sheets;
- Pull away the dirty sheets carefully and tuck the clean ones into the bed;
- Change the pillowcases;
- Help the person back into the middle of the bed and a location of comfort;
- Replace the top sheets and cover.

## Preventing the Spread of Infection

Infections are caused by germs that spread from one person or location to another. They can spread in different ways. Some, like colds and flu, spread when you come in contact with a contaminated surface. Washing your hands the right way and at the right times is very helpful in preventing these kinds of infections. Other infections, like HIV and Hepatitis B, are found in blood and other body fluids. Always taking precautions around blood and other body fluids is the key to stopping these types of infection. Some infections, like Tuberculosis, can even be carried on tiny particles in the air.

Preventing the spread of infection is an important part of hospice care. You need to know that infections can cause disease and complications for the patient, for caregivers, and for others who are living with or visiting the patient.

*What can you do to help prevent the spread of infection? Here are five key points:*

1. Get in the **habit of washing your hands** both before and after doing things like: providing care; eating, drinking, or handling food; using the toilet; covering a cough; or blowing your nose. When you wash your hands, take the time to do it correctly. Following these steps is a good idea:
  - Push up your sleeves and rinse with warm water;
  - Work your hands together with soap for at least 10 full seconds;
  - Get under your nails and cuticles;
  - Rinse well;
  - Dry your hands (*Suggestion: use a clean paper towel to dry your hands; then use a dry paper towel to turn off the faucet.*)
2. Use **extra caution around blood, body fluids, and any sharp objects** (like used syringes). Find out from someone on the hospice team what special safety precautions they recommend.
3. If **personal protective items...** such as gloves or masks... are recommended or specified by the hospice team, be sure you learn how to put them on and take them off correctly, and then use them as called for.
4. Maintain a **clean caregiving environment**. If there is a spill, for example of blood, be sure to clean it up, being careful about avoiding any direct contact. Ask the hospice team about correct disposal of used syringes, bandages, and other contaminated items. And following whatever directions or recommendations they give you.
5. Finally, **work together** on the goal of preventing the spread of infection. Let someone on the hospice team know if you have questions or need help. Make it clear to yourself and others involved in care that you understand this is an important part of the care giving effort you're involved in.

## Using Oxygen Safely

*Basic points for using oxygen safely include:*

- Safe use of oxygen is important;
- The prongs of the nasal cannula must be in the patient's nose;
- If using a face mask, it must fit snugly on the person's face;
- Small pieces of cotton or pads between tubing and skin can lessen irritation if it occurs;
- Understand how to use the equipment and any backup system;
- Oxygen is a drug and must be used only as prescribed by your physician. Treat it just like any other medication your loved one takes. Don't change the amount unless he/she is instructed to do so. Oxygen needs vary with activity;
- Never use petroleum products (e.g. oil or grease) if oxygen equipment is being used because of the risk of combustion. Vaseline is a petroleum based product and should never be used for nasal irritation. Instead, use a water-based moisturizer such as K-Y jelly;
- Make certain that the delivery device (cannula, mask, etc.) is clean to reduce potential infection and to assure adequate oxygen delivery;



- Oxygen tubing should be no longer than 50 feet, because it may decrease the amount of oxygen received;
- If patient or a visitor smoke, the smoker should be at least 10 feet away from the oxygen source and any tubing;
- There should be no open flames (e.g. candle, wood stove, fireplace) within 10 feet of the person using oxygen, all tubing, and the source of oxygen.

## **Types of Oxygen Delivery Systems—Precautions, Instructions**

*There are different ways that oxygen can be provided:*

### **Concentrators**

*These machines take the air and concentrate it into oxygen.*

- Place concentrators 6-12 inches away from curtains, heating units, or open flame;
- Remove any frayed electrical wiring. Do not use extension cords. Concentrators draw as much as 5-6 amps, be careful not to overload circuits;
- Do not use aerosol sprays in the vicinity of the concentrator as they may clog the filter.

### **Liquid Systems**

- Store in a cool, well-ventilated place at least 10 feet from outlets, open flames or other heat sources;
- Do not touch the fill adapter (the area that frosts over) after filling the portable;
- Special precautions are required when traveling with liquid oxygen, especially during hot weather when car temperatures may exceed 200° F. Windows must be left open for ventilation and the car's electrical system must be in good working order to prevent sparks from igniting in a highly combustible atmosphere.

### **Tank Oxygen**

- Store away from heat sources. The pressure inside the tank increases for each 5 degree increase in cylinder temperature;
- Secure tanks to the wall, stand, or other stabilizing device to prevent them from falling over. Because of high pressures inside the tank, damage to the tank or regulator can be dangerous. Do not store in hot, unventilated area, such as trunks of cars, closets, storage units, or under the bed.

*Note: Both liquid and cylinder oxygen must be secured with a seat belt when traveling. Oxygen tanks should not be stored in an area that can reach above 120° F.*

## **Using Restraints**

At times, patients become forgetful and confused. They may move about in ways that put them at risk for injury. Be sure to talk with the hospice team about this. They can help you in promoting patient safety, including deciding whether use of restraints may be necessary and appropriate.

In many cases, there are alternatives which solve the problem without using physical or chemical (by medication) restraint. A bonus with most of these recommendations is that they also improve the quality of life for your loved one. Alternatives to physical or chemical restraint include:

### **Increased Physical Comfort Positioning**

- food or drink
- back rub
- toileting
- appropriate clothing
- glasses, hearing aid, dentures

### Increased Activity Level

- walking
- recreation/social activity
- exercise

### Environmental Changes

- noise reduction
- adjust lighting
- mobility aid (cane, wheelchair)
- change of location
- use electronic bells/signals
- use baby monitors
- make home safe (clear pathways, remove loose rugs, lower water temperature)
- soft, familiar music
- personal space (with familiar objects)
- special furniture
- in supervised area (not left alone)
- confine to a safety-proofed area

### Psychosocial Stimulation

- one to one attention
- reality orientation
- something to hold (give sense of security)
- relaxation techniques (massage, warm bath, touch)

### Guidelines for Use of Restraints

Restraints should only be used when there are no other means available to prevent physical or psychological harm to the person or another person. *Always check with hospice staff or the doctor for specific instructions concerning when and how to use restraints.*

### Home Safety Recommendations

A safe home is important to make the day-to-day activities go smoothly. The phone should be in working order and within reach. A list of key people with phone numbers: MD, Hospice, Pharmacy, and family are helpful to have nearby.

**Fire Safety:** Install working smoke/heat alarms, have fire extinguisher available, avoid smoking in bed and call for help if you smell gas or other burning odors. Prepare a fire escape plan. Practice your escape plan at least twice a year.

**Electrical:** Do not overload the circuits. Do not use frayed cords or faulty switches. Do not stretch cords across pathways.

**Environmental:** Remove throw rugs or secure them to the floor, and keep exits/entrances free from clutter. Maintain adequate lighting. Wear shoes that will not slip. Use non-skid mats. Set hot water heater below 120°. Keep firearms locked and safe. Restrain pets when guests are coming. Never use or clean equipment without instructions. Clear walking areas by removing obstacles and cords from pathway.



*“What lies behind us and  
what lies before us  
are tiny matters compared to  
what lies within us.”*

*—Ralph Waldo Emerson*

## Patient and Family Rights in Hospice Care

Every hospice organization recognizes the critical role of patient/family rights and responsibilities. Although each program will express these differently, the following is an example of what you can and should expect. If you have any questions or concerns, be sure to refer to your provider's own statement of patient/family rights and responsibilities.

### **FHN Hospice Patient and Family Bill of Rights**

As a patient/family of FHN Hospice I have the right to:

1. Be treated with respect, dignity and compassion. To express my feelings and emotions about my approaching death in my own way.
2. Be assured of confidentiality of personal and medical records as well as privacy in treatment and care of your personal needs including who has access to your record, restriction of use and disclosure of health information.
3. Receive necessary information including risks, benefits, costs and alternatives in order to give information consent for treatment or refuse treatment and participate in development and revisions in plan of care and to have family caregivers involved in the plan of my original and provision of care.
4. Receive appropriate assessment and management of pain.
5. Have the intent of an Advance Directive (such as a Living Will or Power of Attorney for Health Care) honored by Hospice and/or to receive information and assistance in completing an Advance Directive.
6. Know the identity and role of those involved in your care as well as information about other organizations with whom Hospice collaborates to provide health care.
7. Register a complaint about your care without being threatened, restrained or discriminated against in any way.
8. To have property treated with respect. Every consideration of my privacy with regard to medical, person, and family matters.
9. Talk in confidence with health care providers and to have your health care information protected. You also have the right to obtain and review a copy of your own medical record and formally request that your physician amend your record if it is not accurate, relevant or complete.
10. A safe and secure healthcare environment. In the event of a medical or healthcare error, you have the right to an explanation and thorough investigation.

*If, for any reason, you are dissatisfied:*

- You are encouraged to first discuss your concerns directly with the person(s) providing your care.
- If this does not resolve your concern, you may use the program's grievance procedure, which usually means getting in touch with the team manager or program director.
- You have the right to pursue your concerns without fear of reprisal. Your provider's goal is to meet your expectations for service and quality. Your comments and concerns will be viewed as an opportunity to improve their services. If you are receiving hospice care at home, you have the right to pursue a complaint by telephoning the *home care hotline* in your state.

## **Patient and Family Responsibilities**

1. Your hospice provider asks that you keep your care providers informed of changes in your health and other caregiving needs.
2. You must provide accurate insurance and financial information, and any changes in them that may occur while receiving services.
3. You will need to sign the appropriate forms for insurance billing.
4. You are asked to participate in planning and guiding your own care, consistent with your abilities and personal values, which assists in developing and maintaining a safe home environment.
5. Please treat staff with the same respect and dignity shown to you.
6. You will be responsible for maintaining medical supervision as required for your home health plan and treatment. The primary caregiver will assume the responsibility to provide for the care of the patient. Hospice cannot provide a 24-hour caregiver.

## **Conversations Near The End of Life**

### **Thinking and Talking About Death Isn't Easy**

What does it mean to be ready for the end of life? What is the spiritual reality of death? Many of us don't even want to think about such questions. However, those who know that life's end is drawing near often begin reflecting on the experience of dying—or of having a loved one die. If you, or someone close to you, are in this position, it can seem a lonely, difficult task. But it doesn't have to be.

### **Questions About Living**

When there is only a short time left in life, there are often choices to make in order to use one's remaining time well.

- What do you still want to accomplish?
- What do you need to do to get your affairs in order?
- Who are the people you want to spend time with?
- Are there letters you want to write, conversations you'd like to have, and matters you need to resolve?
- What will bring you pleasure to this part of your life?

It is good and healthy to think about these questions, and to talk about them with family and friends. Those who know they are going to die soon often have a very high quality of life for the very reason that they are free to focus their energy on what is really important.

### **Questions About Dying**

Death is a mysterious journey for all of us. It makes sense to have questions about the process and what it means. Such questions may include:

- What do I believe about what happens to a person during and after death?
- Are there ways to prepare spiritually for dying?
- What will make me less sad or afraid?
- How do I sum up my life, make peace with who I have been and who I am?
- What kind of funeral, memorial service, or other remembrance do I want after my death?
- Who do I want with me when I die?

These questions and others like them can be painful, but they can also bring great joy and a sense of inner peace. Each of us is different, of course. But many who are experiencing a terminal illness need and welcome persons who do not close off such conversations, but instead, encourage them, listen supportively, and offer to share their own ideas and life experience, when that is helpful.

## Who Can Help?

Over the past twenty years, our culture has become more aware of dying as a “normal” stage of life. We now have persons available with special training to help those at the end of life ask the questions and find the answers that will make a difference.

***Priests, ministers, rabbis, and other leaders of spiritual communities:*** *These people can be a significant resource for persons in their community nearing the end of life, and for their loved ones. Every religious and philosophical community has its own beliefs around death and dying. To talk with someone who can both sensitively listen and also articulate a particular faith position can be a real gift. Many religious leaders are happy to extend themselves, even to those who are not officially a part of their church, synagogue, or organization. Don't be afraid to ask.*

***Chaplains and Pastoral Care Counselors:*** *For those in hospitals, hospice programs, and other care settings, a chaplain or pastoral care professional or volunteer is often available. They are trained to be helpful to people across a wide spectrum of spiritual beliefs. Chaplains are available to both patients and families. Their experience and involvement can provide comfort and support, as well as concrete help, for those facing end-of-life questions. Often, their role is as important in emotional and social issues as it is in spiritual issues.*

***Private therapists:*** Especially when a person or family faces thorny issues—such as unresolved family conflicts—a private counselor or therapist can help. In finding a therapist, you can ask persons you know for referrals. It's usually a good idea to have a “get acquainted” phone conversation with the therapist you are considering to make sure he/she is someone you would be comfortable with.

***Support groups:*** Sometimes, it helps to talk with others who are in the same position as you are. You can share insights, find humor where others may not, support one another. Your local hospital or hospice program probably keeps a list of support groups available in your community.

***Friends and family:*** Family and friends probably do not have special training. They may not even have previous experience being with one who is dying. But if they are willing to get over any discomfort they have addressing the spiritual issues of death and dying, they can be the very best resource available.

## How To Be A Friend To One Who Is Dying

- Let the person decide what you will talk about and when. Let them know you are open to any conversation they'd like to have.
- If your friend wants to engage you in a discussion about spiritual beliefs concerning life and death, be honest about expressing your feelings and beliefs. However, do not challenge or discourage the expressed feelings or beliefs of the dying person. We all have the right to chart our own spiritual journey!
- If you cannot be present in person, call or write letters. Those at the end of life need to know you are thinking of them.
- Don't be afraid to laugh, or to cry. Real emotion can bring healing and peace.
- Sometimes, when a person is too tired to talk, he or she will still appreciate having someone sit quietly in the room. Often, touching—for example, holding hands—becomes an important means of communicating what you're feeling.
- Cards, flowers, or small gifts help the receiver to remember your visit after you are gone.
- Before you visit, check to see what length of visit is appropriate.
- Often doing something fun together is as helpful as a serious conversation.
- Be willing to change your plans or your topic of conversation based on how your friend is feeling at the moment. Be flexible.
- Let those you love know what you treasure about them, why they are important to you, and what memories you especially cherish.

The end of life can contain some of its richest moments and its greatest personal growth. It is not something to fear, but rather a time to be lived with heightened awareness and sensitivity.

## Preparing for Approaching Death

When a person enters the final stage of the dying process, two different dynamics are at work which are closely related and interdependent. On the physical plane, the body begins the final process of shutting down, which will end when all the physical systems cease to function.

Usually, this is an orderly and undramatic, progressive series of physical changes which are not medical emergencies requiring anything other than comfort measures. These physical changes are the natural way the body prepares itself for death. You can aid in this process by enhancing the patient's comfort.

The other dynamic at work is the spiritual and emotional process patients go through at the end of their lives. They begin to release themselves from a lifetime of attachments and often feel moved to resolve unfinished business. This may include tying up loose ends in their relationships or looking for permission to die from their family members. Patients sometimes linger on in their dying process when important issues remain unresolved. Dying cannot be rushed. The person will continue to live until the body has physically shutdown. Working through these emotional and spiritual events, which simultaneously occur with the deterioration of the body, is the normal and natural way a person prepares to die.

Family members can help this process along by following the patient's lead. If he or she wants to communicate with you, be ready to do so. Maintain an affectionate heart for whatever way the patient wants to work. For instance, it may be more beneficial to surround the patient with pictures of whatever religious figures he or she requests, rather than of family photos. This can aid the patient in his or her transition out of this world into the next. This is not the time to attempt to change your loved one, but the time to offer full acceptance, support and comfort.

The physical signs of impending death which follow are offered to help you understand the natural way this event occurs and what you can do to help. Not all these signs and symptoms will occur with every person. Although you may be prepared for the death process, you may not yet be prepared for the actual moment of death. It may be helpful for you and your family to think about and discuss what you will do when the moment occurs. The death of a hospice patient is not an emergency as we usually define it. There is no rush. Nothing must be done immediately.

The signs of death include such things as: no breathing, no heartbeat, release of bowel and bladder, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, no blinking, mouth slightly open. A hospice nurse will come to assist you if needed or desired. If not, telephone support is available.

The members of the hospice team can educate you on this process. Use them as a resource. The members of the hospice team thank you for the privilege of assisting you with the care of your loved one. They salute all you have done to bring comfort and peace to your loved one during these challenging days. The memories hospice staff have of their patients and families are a rich source of satisfaction and inspiration.

## Physical Signs of Approaching Death and Appropriate Responses

**COOLNESS:** The person's hands, arms, feet and legs, may be increasingly cool to the touch and at the same time the color of the skin may change. The underside of the body may become darker and the skin become mottled. This is a normal indication that the circulation of blood is decreasing to the body's extremities and being reserved for the most vital organs. Keep the person warm with a blanket, but do not use an electric blanket.

**SLEEPING:** The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one, hold her/his hand, do not shake or speak loudly, but speak softly and naturally. Plan to spend time with her/him during those times when she/he seems most alert and awake.

Do not talk about the person in the person's presence. Speak to her or him 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 and identity of people surrounding her/him, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak, rather than have the person guess who you are.

Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, "It's time to take your medication." Explain the reason for the communication, such as, "So you won't begin to hurt." Do not use this method to try to manipulate the patient to meet your needs. An example would be trying to coax your loved one into making the disorientation go away, such as, "You remember what I told you yesterday, don't you?"

**INCONTINENCE:** The person may lose control of urine and/or bowel matter as the 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 her/his chest as though marbles were rolling around inside; these sounds may become very loud. This normal change is due to the decrease of 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 and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the 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 metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, in a quiet, natural way, lightly massage the forehead, read to the person, 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 which is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidelines). A cool, moist washcloth on the forehead may also increase physical comfort.

**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 decrease in circulation through the kidneys. Consult with your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

**BREATHING CHANGE:** The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, i.e. shallow breath with a period of not breathing of 5 to 30 seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head and/or turning the person on his/her side may bring comfort. Hold his/her hand. Speak gently.

### **When Death Occurs**

People wish to handle the time of death and the events that follow in different ways. The hospice team's first goal is to help prepare you, so you will know what to expect. Your physical and emotional well-being is as important as the dying person's.

- Call the hospice office. A Hospice nurse or other team member will speak with you and may come to your home. Check with them concerning appropriate notices to your doctor, medical examiner or coroner, etc;
- It may be helpful to have a friend or family member come to be with you;
- If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait several hours before the funeral home comes if you wish to spend time with your loved one's body or want to wait for other family members or friends to arrive;
- If you have any concerns or fears, call the hospice nurse.

### **Signs of death include:**

- No breathing;
- No heartbeat;
- No response to communication;
- Eyes fixed on a certain spot;
- Eyelids slightly open;
- Jaw relaxed and mouth slightly open.

## **Practical Issues When A Person Dies**

### **Notifying others that your loved one has died**

When a loved one dies, some names will come to you immediately as persons who should be contacted. Close family; good friends; the person's minister, priest, or rabbi; their lawyer and physician. Some calls you will want to make yourself. Other calls have to be made, but you do not need to make them. When a death occurs, both your friends and your loved one's friends, as well as other family members, will want to be of assistance. It makes sense to let others help in passing the word. With friends, for example, or a church or community group, often you can make only one call and ask that person to organize informing others from that circle of acquaintances.

If there are many calls to be made, keep a list of who has been contacted. That way, there is less chance someone important will fall through the cracks.

*"Life is pleasant. Death is peaceful.  
It's the transition that's troublesome.*

—Isaac Asimov



## Working with the Funeral Home

Normally, within 24 hours of your loved one's death, you should be in contact with the funeral home to set up an appointment with a funeral director. Funeral homes offer a wide range of services at the time of death. These usually include:

- transporting the body from the place of death to the funeral home;
- preparing the body for burial, arranging for a casket and other necessary items for burial, or arranging for cremation;
- working with the family and, if desired, a priest, rabbi, or minister for a funeral or memorial service;
- providing time and space for visitation and a funeral or memorial service;
- assisting in the preparation of an obituary and funeral notice for the local newspapers;
- completing the necessary paperwork for the death certificate, and obtaining certified copies of the death certificate for the family. (Be sure to ask for an adequate number of certified death certificates.) You will need one for each life insurance policy or pension the person had, and several more for processing the person's Last Will and Testament and other financial business. A good rule of thumb is to request at least ten copies;
- transporting the body and family members (if desired) to the funeral or memorial service and/or to the cemetery.

Some funeral homes also offer support groups and bereavement counseling for family members of the person who has died.

Most funeral directors are professionally trained persons who provide their service with compassion and integrity. The role they play in a community is a necessary one, and most do their work sensitively. However, it is important to realize that funeral directors deal with people who are in an especially vulnerable state. When someone you love has just died, if pre-arrangements have not been made, you need to make quick decisions on painful issues. These issues include whether the person will be buried or cremated, what kind of casket to buy, where to buy a burial plot, what kind of service to have. Some of these decisions may involve the outlay of significant amounts of money and may also be emotionally charged, so they become more complicated.

Though most funeral directors will not deliberately use guilt and emotional manipulation to encourage families to purchase high priced goods and services, the following suggestions will minimize the risk of making decisions about which you feel angry or regretful later on.

*“The only courage that matters  
is the kind that gets you  
from one minute to the next.”*

—Mignon McLaughlin



- Never send one family member alone to see the funeral director. If possible, have two or three family representatives go, one of whom should be more detached from the pain of the loss than a spouse, or sometimes even a child.
- Most funeral homes offer a basic minimum service package. Additional services beyond that are charged individually. Make sure you understand what is included in the basic service, and what will be charged as additional services. Have the funeral director spell out the charges in writing. If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.
- Money does not equal love. Many people think they must buy an expensive casket or provide a lavish funeral to show their love for the one who has died. This is not true. Buy only those goods and services that seem reasonable to you.

The appointment with the funeral director is usually a part of the business of death that people dread. Arranging for caskets and funeral notices is no one's favorite chore. Try to schedule your visit far enough after your loved one's death that you and significant others have had a night's sleep and have had some time to talk among yourselves about the kinds of arrangements that seem best to you.

If your loved one has joined a memorial society or entered into some other form of prepaid funeral plan, you and other family members will have fewer decisions to make. However, you will also have less control. If you are uncomfortable with the arrangements that have been made, you may have little choice but to accept them and understand that they represent your loved one's wishes.

### **Planning a funeral or memorial service**

After one they love has died, most people find it helpful to participate in some structured ritual of celebration, remembrance, and letting go of the person who has died. Depending on the religious tradition and individual tastes of the deceased person and his or her family, this ritual might range from a Requiem Mass followed by an elaborate wake, to setting a time for family members and friends to get together informally to talk about the one who has died. Such services, both formal and informal, can be a source of comfort and strength, gathering together the community of grief to laugh and cry and remember together.

Below is a list of questions which will help you in planning a funeral or memorial service for a close friend or relative who has died.

- Did your loved one leave any specific instructions about the kind of service that he/she would want? Did those instructions include specific requests for readings, music, a person to preside, or a place where the service was to be held?
- When will it be convenient for the service to take place? Do close family and friends have schedules which have to be worked around in planning the time and place of the service?
- Where will the service take place? If the person belonged to a church, synagogue, or other religious community, when can it schedule a service?
- Who will officiate at the service? Will it be a minister, priest, rabbi, family member, or friend? Do you want an organist, soloist, or other provider of music, and how will those arrangements be made?
- Are there readings, music, pictures, or any other elements which you think would be especially meaningful to you and others as part of the ceremony?
- Do you want to choose someone to deliver a formal eulogy? Do you or other friends or family members wish to offer some personal words of remembrance at the service?
- Do you wish to have visiting hours (a time when people can see the body, say a private good-bye, and speak with the family) before the service? This custom varies from community to community.
- Will there be any kind of reception or other informal gathering of friends and family after the service? Where will it be held?

If you work through a church or other religious community, your contact in that community will undoubtedly have other questions to ask you about the service. However, it is best to think about the questions outlined above before you meet with whoever will be in charge so that you have some idea of what you want.

### **Other practical issues**

Along with the major issues of dealing with the death when it occurs—talking with the funeral director, and planning for a funeral or memorial service—there are other practical tasks large and small which should be attended to in the days and weeks following your loved one's death.

- You will want to contact the person's lawyer regarding the content of his or her will (if one exists) and any other legal business that needs to be attended to.
- You (or whoever has been appointed under the person's will as personal representative of the estate) should contact the person's bank, financial planner, pension administrator, life insurance company, and any others with whom the person had significant financial dealing to inform them of the death. Many of these persons will want certified copies of the death certificate, especially if they are paying out benefits or transferring them to a surviving spouse or joint tenant.
- You should remember to cancel club memberships and magazine subscriptions and have mail delivery stopped or transferred.
- Outstanding bills need to be collected and paid, but this should always be coordinated with other aspects of handling the estate.
- For many families, one of the difficult things to do is to go through your loved one's personal possessions—clothing, papers, mementos, furniture—in order to sort it, sell or give away what the family does not want to keep, and make arrangements for the rest. Like visiting the funeral home, this is a task that is easier if shared among two or more family members.

Taking care of all the business that needs to be sorted out after a death can take weeks or even months, depending on how the person's affairs were organized. It is tiring and emotionally draining work. If you can, share the responsibilities with other family members, do hard tasks with another person, and don't take on too much at one time. It is normal to feel overwhelmed at times with the finishing up of things.

## **Experiencing Grief and Loss**

### **Anticipated Grief and Loss**

Watching someone you love decline in health is a painful process. When death is anticipated, both the patient and their loved ones may experience a normal form of grief. It is called *anticipatory grief*, and is similar to the process of grief following a loss.

#### **Some of the aspects of anticipatory grief that you may notice include:**

- Heightened fear, anxiety and depression;
- Increased concern for the well-being of the terminally ill person;
- Imagining the actual event of the death;
- Attempts to adjust to the changes that may occur after the death.

#### **Although anticipatory grief is a painful process, having some warning prior to the death can allow for several things:**

- Absorbing the reality of the loss over a period of time;
- Saying good-bye and completing other unfinished business with the dying person;
- Reassigning the family roles of the dying person;
- Gradual withdrawal of emotional energy invested in the dying person.

**Because you are losing an important person in your life, many difficult changes can occur including:**

- Loss of energy and vitality;
- Family members may feel a sense of isolation, as the family focuses their energies on caring for their dying loved one;
- The best and worst of family characteristics may come out at this time;
- Communication can break down and misunderstanding can increase tension;
- Limited finances can increase stress, as medical expenses increase;
- Uncertainty about the dying process and feelings of lack of control can be overwhelming.

There are many ways that you can care for yourself during your loved one's illness that can lessen the negative aspect of anticipatory grieving. Plan to have some time for yourself everyday. Seek out ways to nurture yourself, including: eating well, sleeping enough, exercising, and spending time with a friend for hugs and laughs. It is only possible to care for others if you first take care of yourself.

There are a wide variety of feelings and behaviors which can be experienced in the grief process. Not everyone will respond to loss in the same way. It is helpful to know that the following characteristics can be a normal part of the grief experience:

### **Feelings**

Feelings that are part of the grieving process include: shock; numbness; sense of unreality; anger; irritability; guilt; self reproach; sadness; depression; anxiety; fear; hysteria; helplessness; vulnerability; low self-esteem; loneliness; relief; feelings of being crazy; mood swings; intensity of all feelings.

### **Physical Sensations**

Physical sensations experienced during grief include: hollowness in the stomach; tightness in the chest and throat; dry mouth; over sensitivity to noise; dizziness; headaches; shortness of breath; weakness in the muscles; lack of energy; fatigue; excess of nervous energy; heart pounding; heavy or empty feeling in body and limbs; hot or cold flashes; skin sensitivity; stomach and intestinal upsets; increase in physical illness.

### **Thought Patterns**

Grief-related thought patterns include: disbelief; sense of unreality; preoccupation; confusion; lack of ability to concentrate; seeing, hearing; feeling the presence of the deceased; thoughts of self destruction; problems with decision making.

### **Behaviors**

Behaviors while experiencing grief include: appetite and sleep disturbances; absent-minded behavior; social withdrawal; avoiding reminders of the loss; dreams of the loss; searching and calling out for the deceased; restlessness; sighing; crying; visiting places that are reminders of the loss; treasuring or carrying objects that belonged to the deceased; change in sexual activities; need for touch; hugs; contacts with others; increased sensitivity to positive and negative attention; picking up mannerisms of the deceased; exhibiting symptoms of deceased's illness.

### **Social Changes**

Social changes brought on by a grieving process include: Either an increased desire for support of close friends or a withdrawal from friends and family; increased dependency on others; a need for acting normal around others; a need for relationships apart from those related to grief; being self-absorbed (no energy for or interest in others); marital difficulties—especially with the death of a child; role changes; role reversals; change in social patterns and status; hypersensitivity to topics of loss; need for rituals.

## Suggestions for Coping With Grief

- **Allow Yourself to Feel Your Feelings**  
Someone close to you has died. Many emotions may arise. It's okay to feel angry, depressed, or even feel a sense of relief at the time of death.
- **Access Your Support System**  
Reach out to people who are supportive to you. Family, friends, support groups, clergy or a therapist may be helpful.
- **Share Your Feelings of Grief**  
Talking about your feelings can be a relief. Don't hide your emotions from those who care about you.
- **Educate Yourself About Grief Issues**  
Reading literature about grief can help you in understanding what you are experiencing.
- **Take Care of Your Physical Self**  
Remember that your emotional state can be affected by your physical state. Attempt to eat balanced meals, get adequate sleep, and do some form of exercise each day.
- **Avoid Alcohol and Other Substances Not Prescribed By Your Physician**  
Although they may numb the emotional pain initially, drugs and alcohol may prolong, delay and complicate your grief.
- **Give Yourself Permission to Say "No"**  
Try not to rush or take on new responsibilities.
- **Be Patient and Gentle with Yourself**  
Healing from grief takes time. Your grief may not look like the grief of others around you. Respect your own individual grief style.

## Helping Children Deal With Their Grief

Children re-grieve. They work through their grief in cycles. Each time a new developmental milestone is attained, children will integrate and use their newly acquired skills to gain further understanding of their grief. The child's history of loss and coping strategies, as well as the child's age and developmental stage will affect the child's re-grieving experience.

Children are often repetitive in their grief. By asking the same questions over and over again, they are able to come to terms with their grief. Answering a child's repeated questions with the same information gives the child a sense of stability, constancy, and trust in their relationship with you.

Children grieve as part of a family. When a loved-one is diagnosed with a terminal illness, it affects the way in which the family functions. Family roles and responsibilities may adjust to accommodate the new needs in the family structure. Children may grieve not only for the dying loved one, but also for the secondary losses which result, for example; changes in routine, decreased attention from parents, increased individual responsibilities, etc.

Young children are concrete thinkers. Adults frequently use euphemisms (the substitution of a "good" term in place of one considered "bad") when describing death or dying to soften the blow of this harsh reality. Adults need to be careful when using euphemisms, so that children aren't even more scared or further confused. For instance, if an adult says, "We lost Grandma today," a child may want to know why people aren't looking for her. A child may also wonder, "If I get lost, will anyone come looking for me?" Similarly, an explanation like "Dad is sleeping peacefully now," may create in the child a fear of sleeping.

## **You can help children cope with death and dying**

Children need clear and honest information about their loved one's diagnosis (cause of illness) and prognosis (prediction of the outcome of the illness) at a level which they can understand.

Include children in discussions of the patient's condition, changes in health status, and of the signs and symptoms of approaching death, etc.

Encourage children to express their feelings directly. Talk with them about their perceptions and understanding of what is happening with their loved one. Acknowledging your own feelings lets your children know it is okay to experience and express theirs.

Offer choices whenever possible. For instance: helping with care giving at an age-appropriate level; attending the funeral service; viewing the body; participation on good-bye rituals/symbols, etc.

Let the hospice staff know if you have concerns or questions or are experiencing difficulties.

## **Children's Grief Web Site**

If there are children involved in your hospice care experience, there is a wonderful web site you should know about and visit. You'll find it on the world wide web at [www.safecrossings.org](http://www.safecrossings.org).

## **Emergency Preparedness Plan**

### **Disaster Supplies Kit**

There are six basics you should stock for your home:

Water, food, first aid supplies, clothing, bedding, tools, emergency supplies, and special items.

Keep items in an easy to carry container. Store your kit in a convenient place known to family.

### **Water**

- Store water in plastic containers such as soft drink bottles
- Store one gallon of water per person per day
- Keep at least a three-day supply of water per person

### **Food**

- Store at least a three-day supply of non-perishable food
- Ready-to-eat canned meats, fruits, and vegetables
- Canned juices
- Staples (salt, sugar, pepper, spices)
- High energy foods
- Vitamins
- Food for infants
- Comfort/stress foods

### **First Aid Kit**

- Bandages
- Germicidal hand wipes
- Antiseptic wipes
- Non-latex gloves
- Adhesive tape
- Antibacterial ointment
- Cold packs
- Scissors



*“The strongest have their moments of fatigue .”*

— Friedrich Nietzsche

## Non-Prescription Drugs

- Aspirin or non-aspirin pain reliever
- Anti-diarrhea medication
- Antacid
- Laxative

## Tools and Supplies

- Battery operated radio
- Extra batteries
- Flashlight
- Non-electric can opener
- Fire extinguisher
- Matches in water-proof container
- Signal flare
- Paper, pencil
- Medicine dropper

## Sanitation

- Toilet paper, towelettes
- Personal hygiene items
- Plastic garbage bags and ties
- Plastic bucket with tight lid
- Household chlorine bleach

## Clothing and Bedding

- At least one complete change of clothing and footwear per person
- Blanket or sleeping bags
- Thermal underwear
- Hat and gloves

## Special Items

- For baby—formula, diapers, bottles
- For adults—medications, denture needs, extra eye glasses

## Entertainment

- Games and books

## Tips

- Keep items in air-tight plastic bags
- Change your stored water supply every 6 months
- Replace your stored food every 6 months
- Replace batteries
- Update clothing, etc.

## Chemical Emergencies

If an accident involving hazardous materials occurs:

- You will be notified by the authorities what steps to take;
- You may hear a siren or be called by telephone, or emergency personnel may drive by giving instructions over a loudspeaker;
- Go indoors and listen to local Emergency Alert System stations for emergency instructions.



*Courage is not the absence of fear, but rather the judgment that something else is more important than fear.*

—Ambrose Redmoon

## **Fire**

- Determine at least two ways to escape from every room in your home;
- Practice your escape plan at least twice a year;
- Use test button to check each smoke alarm monthly;
- Have 1-2 fire extinguishers in your home;
- Escape safely; once out—stay out! Call fire department from neighbor;
- If exits are blocked; stay in room with door closed. Signal for help using bright colored cloth at the window. If there's a telephone in the room, call fire department and tell them where you are.

## **Terrorism**

- Create an emergency communication plan;
  - Choose an out-of-town contact person your family will call or email to check on each other;
- Establish a meeting place;
- Assemble a disaster supplies kit;
- Remain calm and be patient;
- Follow advice of local emergency offices;
- Listen to your radio or television for instructions;
- If disaster occurs near your home, check damage using a flashlight;
- Shut off any damaged utilities;
- Confine pets;
- Call your family contact but don't tie up phone line.

## **Thunderstorms, Tornadoes, Lightning**

- Prepare a home tornado plan;
- Pick a place where family members could gather: basement, center hall-way, bathroom, closet on lowest level;
- Assemble your disaster supplies kit;
- Stay tuned for storm warnings (Radio or TV);
- When warning is issued, go to safe place you picked;
- If outside, hurry to basement or lie flat in ditch;
- If in car or mobile home, get out immediately and head for safety;
  - After storm passes:
- Watch out for fallen power lines;
- Listen to radio for information and instructions;
- Use flash light to inspect for damage;
- Do not use candles at any time;

## **Winter Storm**

- Have extra blankets on hand;
- Ensure that each member of your household has warm coat, gloves, mittens, hat, and boots;
- Assemble your disaster supply kit;
- Stay tuned for storm warning;
- Avoid unnecessary travel;
- Stay indoors;
- If you must go outside, wear several layers of light-weight clothing;
- Walk carefully on snowy, icy sidewalks;
- If you need to drive by vehicle, carry disaster kit in trunk; keep gas tank full; let someone know your destination and route.







## More Resources

Additional online publications dealing with support services for independent and assisted living; free eldercare forms; eldercare searches for nursing homes, home health providers, and assisted living communities.

[www.SeniorClix.com](http://www.SeniorClix.com)

Comprehensive collection of online resources for older adults and caregivers; search for national and local eldercare resources.

[www.elderweb.com](http://www.elderweb.com)

**National Eldercare Locator**—information and referral service offered by the U.S. Administration on Aging.

1-800-677-1116

**Administration on Aging**—Broadest range of resources and links for aging-related issues and needs.

[www.aoa.gov](http://www.aoa.gov)

**Medicare**—information of all types related to Medicare; maintained by Healthcare Financing Administration.

1-800-MEDICARE  
[www.medicare.gov](http://www.medicare.gov)

**National Hospice and Palliative Care Organization**—national database of member hospice care providers.

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

*Lessons from the Dying*, Rodney Smith, MSW, 1998, Wisdom Publications; a valuable book of practical stores, lessons, and meditations.

1-800-272-4050

**Safe Crossings**—resources for helping children Deal with their grief when a parent, grandparent, or sibling dies.

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

**ISHO**, Illinois State Hospice Organization

[www.il-hpco.org](http://www.il-hpco.org)

## **The FHN Hospice Vision:**

Create an awareness and acceptance of death and bereavement as part of life's experience.

### *"A Special Way of Caring"*

FHN Hospice is a concept of care providing non-curative, yet supportive service—We care for the physical, emotional, social, and spiritual needs of our patients and their families as they deal with this period of illness and bereavement. Our emphasis is to assist families who desire to care for their loved one at home during the final phases of life.

FHN Hospice is committed to providing sensitive, comforting care to terminally ill patients and their families in Carroll, JoDaviess, Ogle, Stephenson, and Winnebago counties.

## **Donations**

Donations to FHN Hospice are accepted and very much appreciated. Contributions help provide staff education, meals, Life-Line, supplies, and much more...for patients and families in need. Donations may be directed to FHN Foundation, 1045 W. Stephenson Street, Freeport, IL 61032, 815-599-6900.

## **A program of FHN Memorial Hospital**

**Hospice can be reached 24 hours a day at**

**815-599-7240**

**Toll Free 877-873-3621**



*"How far you go in life depends on your being tender with the young, compassionate with the aged, sympathetic with the striving, and tolerant of the weak and the strong—because someday you will have been all of these."*

*—George Washington Carver*



815-599-7240 • 24 Hours a Day  
Toll Free 877-873-3621

## **The FHN Hospice Program Philosophy**

Hospice accepts death as a natural part of the life cycle. The purpose of the Hospice program is to serve persons with a life-threatening illness and those supporting them. The care available through the Hospice program includes skilled medical and nursing care and an interdisciplinary team approach to meeting medical, social, psychological, and spiritual needs.

The Hospice program is concerned with symptom management that maximizes patient comfort, enhances feelings of self-worth and well being, and encourages patient participation in decisions affecting his/her living and dying. The program supports both patient and family as their activities and relationships undergo change. The support continues into the period of grief and bereavement.

Based on this philosophy we make the following commitments to patients and families regarding the care we provide:

- You will have the best medical treatment, aiming to prevent exacerbation, improve function and survival, and ensure comfort.
- We will help you manage shortness of breath, pain or other symptoms in an effort to promote comfort.
- Your care will be continuous, comprehensive, and coordinated.
- You and your family will be prepared for everything that is likely to happen in the course of your illness.
- Your wishes will be sought, respected, and, whenever possible, followed.
- We will help you consider your personal and financial resources and will respect your choices about the use of your resources.
- We will do all we can to see that you and your family will have the opportunity to make the best of every day.



*Each moment is mine to  
make as beautiful or as painful as I choose.*

—Anonymous



**815-599-7240**  
**Toll Free 877-873-3621**