

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.