

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.