

Frequently Asked Questions

What is Hospice?

Hospice care is a program of care that promotes the quality of life during a life-threatening illness. Hospice recognizes dying as a normal process. Hospice provides comfort when care of illness is no longer possible. Hospice neither hastens nor postpones death. Physical, emotional and spiritual care is provided to both the patient and family.

What is the role the family and primary caregivers play?

The family and primary caregiver continue to provide care and support to the patient. Hospice care is intended to supplement this care, not to replace it. Hospice team members are ready and willing to address any concerns and offer help through care planning. Our team instructs the family and primary caregiver regarding symptom management.

How do I know if insurance will cover hospice care?

Anyone with Medicare Part A is covered for hospice services without an out of pocket expense for covered services related to the terminal diagnosis.

When a Medicare-eligible patient who is an enrollee of a Medicare participating managed care organization (MCO) elects hospice care, the hospice services must be provided through a Medicare-approved hospice, and the individual must meet the eligibility requirements specified by Medicare. The patient does not need a referral from the MCO and is not required to disenroll from the MCO. Medicare pays the hospice for hospice services and the MCO pays for attending physician services and services not related to the patient's terminal illness. In addition, MCOs are required to inform enrollees about the availability of hospice care if: a) a Medicare-certified hospice is located in the MCO's service area; or b) it is common practice to refer patients to hospice programs outside such service area.

What Are the Advantages of Hospice Care?

- Hospice care is a cost-effective alternative to the high costs associated with hospitals and traditional institutional care.
- Hospice care allows terminally ill patients and their families to remain together in the comfort and dignity of their home.
- Hospice care relies on the combined knowledge and skill of an interdisciplinary team of professionals, including physicians, nurses, home care aides, social workers, counselors, and volunteers.
- Hospice is the preferred choice of health care delivery for the terminally ill and their families.
- Hospice treats the person, not the disease; focuses on the family, not the individual; and emphasizes the quality of life, not the duration.

Who Pays for Hospice Care?

Hospice services are covered under Medicare, and currently 45 states, including Louisiana, offer hospice care as an option under their Medicaid programs. In addition, hospice care is a covered benefit under most private insurance plans, HMOs, and other managed care organizations. Military personnel and their dependents are covered for hospice under CHAMPUS. Hospices continue to rely heavily on grants and community support to fund unreimbursed care and hospice services for patients with little or no insurance.

Frequently asked questions about grief.

The journey through grief is a highly individual experience. Rather than focus on a timeline it is perhaps more helpful to focus on its intensity and duration. Initially grief is overwhelming and people can feel out of control. With time people find they have more ability to choose when they access memories and emotions. The intensity of grief is related to the degree of attachment to the person, the type of relationship and other factors such as understanding and social support, personality and specific details of the bereavement.

Am I going mad?

It will certainly feel like it at times! Particularly if the individuals' need to grieve is out of step with social and cultural expectations. Grief affects people physically, emotionally, psychologically and spiritually. People may be required to make adjustments to their lives, e.g., learning new skills, at a time when they feel least able to do so. Validation and permission to grieve are powerful comforts to a bereaved person's experience.

Do I have the right to inflict this on others?

What can I expect of them and they of me? Others will feel intensely uncomfortable with the emotion and the pain of the bereaved to the point of feeling helpless. The anxiety this causes may mean that the bereaved person will be avoided & further increasing the possibility of them feeling isolated or being avoided or they may wish to take over details to protect the person from further pain. It is important that the grieving person is assertive about their needs and wishes, and it is helpful if they communicate with family, friends, and colleagues rather than leave them guessing about what would be useful and comforting. Never underestimate the power of listening and being a warm presence. There are no magic words or actions. Trust your ability to care taking into account your relationship with the person you are trying to help.

Is there a right way and a wrong way of coping with grief?

People are individuals with personalities and life experiences, which influence the way in which they deal with grief. People's style of grieving must be respected and in this sense there is no right or wrong way of coping. However it is generally believed that the amount of support people receive can ameliorate some of the impact of grief and facilitate recovery. People often have an awareness about what they need to do to feel better but feel inhibited or judged and don't act on their inclinations. Talking about what is happening, what they are going through, expressing emotion and existing in a supportive and accepting climate is generally helpful. Cultural factors may impact on a person's feelings of a "right" or "wrong way".

How do I know I need help?

Reassurance from others who have also experienced grief and an understanding of what people have commonly undergone when grieving can be a helpful yardstick. Any continued fears or anxieties about your well being or thoughts of self-harm should be addressed by seeking help. Prolonged intense emotion or obsessional thought or behavior that make functioning difficult may also require help.

Stages of grief: Grief does not follow a linear pattern. It is more like a roller coaster, two steps forward and one step back. Ultimately people manage to integrate the experience to the point of having a new life arising from the old. The loss remains and is always remembered but the intensity is no longer disabling or disorganizing.

Much of grieving is about expressing emotion- some may be unfamiliar, and unacceptable to self or others, e.g., rage, guilt, remorse. Finding a safe place and an accepting person for support to work through all the effects of bereavement is important. The amount of support available from family and friends may be limited if they too are grieving. Misunderstandings can arise when people are at different points within the grief experience. External supports may then become a vital factor in surviving and continuing on. It is important to know that you can survive the experience and that the new life that eventually comes about may have very positive effects despite the difficulty of arriving at this point.

Does counseling help?

It is important to say that grief is a normal response to loss and that people frequently get through with the loving support of family and friends. However for a variety of reasons it may be necessary to seek professional help in the form of counseling. Counseling may initially intensify painful feelings as the external distractions are removed and the client is able to focus on their experiences and explore them fully. People who are grieving may need to talk about their story over and over again and are often concerned about the 'wear out' factor on family and friends, especially if details are very distressing. Equally they may find that others have unrealistic expectations of their recovery or experiences. . Where people have to continue on in roles as parents or careers it may provide valuable time-out for their own need to grieve and receive support. A supportive, safe and accepting environment and time set aside regularly can make a great difference. It may provide comfort and hope at a time of great confusion and crisis.

How can I help the bereaved?

By being there

By tolerating silences

By listening in an accepting and non-judgmental way

Avoid the use of cliches such as "Think of all the good times", "You can always have another child" etc

By encouraging them to talk about the deceased

Be practical in your offer of support by minding children or cooking

By mentioning the dead persons name

Accept that tears are normal and healthy

Don't try to fill in conversations with a lot of outside news

Remember that grief may take many years to work through

Acknowledge birthdays, death dates, anniversaries etc

By accepting that you cannot make them feel better.

What can I do if I am the patient?

Terminal illness presents human beings with an exceedingly difficult and contradictory challenge; you are dying, you know you are dying, yet it is your nature to want to live. These thoughts are intended to help you deal with this tension and to continue to live even though you are dying.

Acknowledge You Are Dying. Acknowledging you are dying is the first step to living the rest of your life. If the onset of your illness was sudden or unexpected, you will likely feel shock and numbness at first. This is a natural and necessary response to painful news. You can only cope with this new reality in doses. You will first come to understand it with your head, and only over time will you come to understand it with your heart.

To acknowledge you are dying is to let go of the future. It is to live only in the present. There is no easy way to do this, and you will probably struggle with this task every day until you die. Know that if you work at acknowledging the reality of your coming death, however, instead of denying it, you will open your heart and mind to the possibility of a new, rich way of living.

Discovering that you are dying naturally makes you take inventory of your life. You have a right to have questions, fears and hopes. Illness establishes new directions and often causes some questioning of old directions. New thoughts, feelings and action patterns will emerge. The unknown invites you to question and search for the meaning of your life, in the past, present and future.

Accept Your Response to the Illness. Each person responds to news of terminal illness in his or her unique way. You, too, will have your own response, be it fear, excitement, anger, loss, grief, denial, hope or any combination of emotions. Becoming aware of how you respond right now is to discover how you will live with your terminal illness.

Don't let others prescribe how you feel; find people who encourage you to teach them how you feel. After all, there is no right or wrong way for you to think and feel. Respect Your Own Need For Talk, For Silence You may find that you don't want to talk about your illness at all. Or you may find that you want to talk about it with some people, but not with others. In general, open and honest communications is a good idea. When you make your thoughts and feelings known, you are more likely to receive the kind of care and companionship you feel will be most helpful to you. But if you don't want to talk about your illness, don't force yourself. Perhaps you will be able to open up more later on, after you have lived with the reality of your illness for a time.

Your family and closest friends deserve to know that you are dying. Tell them when you feel able to. If you simply cannot bring yourself to tell them, find a compassionate person with whom you can entrust this important task. Be aware that everyone will react differently to your news, just as each terminally ill person reacts differently to his or her own illness. Many will be shocked. Many will cry. Some will refuse to believe it. Some will spring into helpful action by running errands for you, offering to clean your house, etc. Many will not know how to respond. Because they don't know what to say or do, or because your illness may arouse their own fears of mortality, they may even avoid you altogether.

Know that their apparent abandonment does not mean they don't love you. Even children deserve to be told. As with all people, children can cope with what they know. They cannot cope with what they don't know. Be honest with them as you explain the situation in language they will understand. Don't over explain, but do answer any questions they may have. Be an Active Participant in Your Medical Care Many people are taught as "patients" to be passive recipients of the care provided by medical experts. But don't forget this - this is your body; your life. Don't fail to ask questions that are important to your emotional and physical well-being out of fear that you will be "taking up someone's time."

Learn about your illness. Visit your local library and consult the medical reference books. Request information from educational associations, such as the National Cancer Institute or the American Heart Association. Ask your doctor, nurses and other caregivers whenever you have a question. If you educate yourself about the illness and its probable course, you will better understand what is happening to you. You will be better equipped to advocate for personalized, compassionate care. You

may not be in control of your illness, but you can and should be in control of your care.

Be Tolerant of Your Physical and Emotional Limits. Your illness will almost surely leave you feeling fatigued. Your ability to think clearly and make decisions may be impaired. And your low energy level may naturally slow you down. Respect what your body and mind are telling you. Nurture yourself. Get enough rest. Eat balanced meals. Lighten your schedule as much as possible.

Say Good-bye. Knowing you will die offers you a special privilege: saying good-bye to those you love. When you feel you are ready, consider how you will say good-bye. You might set aside a time to talk to each person individually. Or, if you are physically up for it, you might have a gathering for friends and family. Other ways of saying good-bye include writing letters, creating videotapes and passing along keepsakes. Your survivors will cherish forever your heartfelt good-byes. **Find Hope** When people are seriously ill, we tend to get caught up in statistics and averages; How soon will the illness progress? How long do I have left? These can be helpful to know, but they don't always provide spiritual and emotional comfort. Even if you are certain to die from this illness, you can find hope in your tomorrows, your next visit from someone loved, your spirituality.

Hope means finding meaning in life, whether that life will last five more days, five more months or five years.

Embrace Your Spirituality. If faith is part of your life, express it in ways that seem appropriate to you. You may find comfort and hope in reading spiritual texts, attending religious services or praying. Allow yourself to be around people who understand and support your religious beliefs. If you are angry at God because of your illness, realize that this is a normal and natural response. Find someone to talk to who won't be critical of whatever thoughts and feelings you need to explore. **Reach Out For Support** Many of us grew up believing, "Do it on your own so you don't have to depend on anyone else." But confronting a terminal illness cannot and should not be done alone. As difficult as it may be for you, you must reach out to your fellow human beings. Most of us know whom we feel comfortable turning to when we are under stress.

Whom do you turn to? Give yourself permission to reach out for prayers, support and practical assistance. Hospices are an indispensable resource for you. They are well staffed and trained to help both the dying person and the dying person's family. Their mission is to help the dying die with comfort, dignity, and love, and to help survivors cope both before and after the death. They often offer support groups for people with life threatening illness. You might also consider seeing a counselor one-on-one. Whatever you do, don't isolate yourself and withdraw from people who love you.

What are Advance Directives?

"Advance directive" is a general term that refers to your oral and written instructions about your future medical care, in the event that you become unable to speak for yourself. Each state regulates the use of advance directives differently. There are two types of advance directives: a living will and a medical power of attorney.

What is a "living will"?

A living will is a type of advance directive in which you put in writing your wishes about medical treatment should you be unable to communicate at the end of life. Your state law may define when the living will goes into effect, and may limit the

treatments to which the living will applies. Your right to accept or refuse treatment is protected by constitutional and common law.

What is a medical power of attorney?

A medical power of attorney is a document that enables you to appoint someone you trust to make decisions about your medical care if you cannot make those decisions yourself. This type of advance directive may also be called a "health care proxy" or "appointment of a health care agent." The person you appoint may be called your health care agent, surrogate, attorney-in-fact, or proxy. In many states, the person you appoint through a medical power of attorney is authorized to speak for you any time you are unable to make your own medical decisions, not only at the end of life.

Why do I need an advance directive?

Advance directives give you a voice in decisions about your medical care when you are unconscious or too ill to communicate. As long as you are able to express your own decisions, your advance directives will not be used and you can accept or refuse any medical treatment. But if you become seriously ill, you may lose the ability to participate in decisions about your own treatment.

What laws govern the use of advance directives?

Both federal and state laws govern the use of advance directives. The federal law, the Patient Self-determination Act, requires health care facilities that receive Medicaid and Medicare funds to inform patients of their rights to execute advance directives. All 50 states and the District of Columbia have laws recognizing the use of advance directives. The booklet, "Questions and Answers: Advance Directives and End-of-Life Decisions," available from Choice In Dying, offers more information.

What is Grief?

Grief is a normal response to loss. It can be the loss of a home, job, marriage or a love one. Often the most painful loss is the death of a person you love, whether from a long illness or from an accident or an act of violence.

This guide will help you understand the grief you and others may feel after a death, whether sudden or anticipated. We hope this guide will help you realize that these feelings are not unusual and things can get better. You are not alone.

The Grieving Process

Grief is painful and at times the pain seems unbearable. It is a combination of many emotions that come and go, sometimes without warning. Grieving is the period during which we actively experience these emotions. How long and how difficult the grieving period is depends on the relationship with the person who dies, the circumstances of the death, and the situation of the survivors. The length of time people grieve can be weeks, months, and even years. One thing is certain: grief does not follow a timetable, but it does ease over time.

Because grief is so painful, some people try to "get over" a loss by denying the pain. Studies show that when people don't deal with the emotions of grief, the pain does not go away. It remains with them, and can turn up in unrecognizable and sometimes destructive ways. Understanding the emotions of grief and its feeling and symptoms are important steps in healing and in helping others who may be grieving.

The Feelings and Symptoms of Grief

Experts describe the process of grieving and the emotions of grief in various ways. The most commonly described reactions are: Shock, Denial, Anger, Guilt, Depression, Acceptance, and Growth. Some people experience the grieving process in this order. Most often, a person feels several of these emotions at the same time, perhaps in different degrees.

Shock

If the death comes suddenly, as in an accident or murder, shock is often the first response people feel. Even if the death is anticipated, there may be disbelief at its finality. A person may be numb, or, like a robot, be able to go through the motions of life while actually feeling little. At the same time, physical symptoms such as confusion and loss of appetite are common.

Denial

Shock and denial are nature's way of softening the immediate blow of death. Denial can follow soon after the initial shock. People may know their loved one has died, but some part of them can't yet accept the reality of the death. It is not uncommon to fantasize that the deceased will walk through the door, as if nothing has happened. Some people leave bedrooms unchanged or make future plans as if the loved one will participate, just as in the past.

Anger

Anger is normal. It may be directed at the deceased for leaving and causing a sense of abandonment, or at the doctors and nurses who did not do enough, or at a murderer who killed without remorse. People of faith may feel anger at God, for allowing so much pain and anguish. Anger may also be directed at oneself for not saving the life of the loved one. It can be a mild feeling or a raging irrational emotion. It can test one's faith in religion or even in the goodness of life.

Guilt

Few survivors escape some feeling of guilt and regret. "I should have done more" are words that haunt many people. Were angry words exchanged? Most people are very creative in finding reasons for guilt. So many things could have been done differently "if only I had known."

Sadness

Sadness is the most inevitable emotion of grief. It is normal to feel abandoned, alone and afraid. After the shock and denial have passed and the anger has been exhausted, sadness and even hopelessness may set in. A person may have little energy to do even the simplest daily chores. Crying episodes may seem endless.

Acceptance

Time alone will not heal grief. Acknowledging the loss and experiencing the pain may free the survivor from a yearning to return to the past. Accepting life without the lost loved one may give way to a new perspective about the future. Acceptance does not mean forgetting, but rather using the memories to create a new life without the loved one. Hoping for things to be as they were may be replaced by a search for new relationships and new activities.

Growth

Grief is a chance for personal growth. For many people, it may eventually lead to

renewed energy to invest in new activities and new relationships. Some people seek meaning in their loss and get involved in causes or projects that help others.

Some people find a new compassion in themselves as a result of the pain they have suffered. They may become more sensitive to others, thus enabling richer relationships. Others find new strength and independence they never knew they had. After the loss, they find new emotional resources that had not been apparent before.

The Experience of Grief

Grieving people have two choices: they can avoid the pain and all the other emotions associated with their loss and continue on, hoping to forget. This is a risky choice, since experience shows that grief, when ignored, continues to cause pain.

The other choice is to recognize grieving and seek healing and growth. Getting over a loss is slow, hard work. In order for growth to be possible, it is essential to allow oneself to feel all the emotions that arise, as painful as they may be, and to treat oneself with patience and kindness.

Feel the Pain.

Give into it - even give it precedence over other emotions and activities, because grief is a pain that will get in the way later if it is ignored. Realize that grief has no timetable; it is cyclical, so expect the emotions to come and go for weeks, months or even years. While a show of strength is admirable, it does not serve the need to express sadness, even when it comes out at unexpected times and places.

Talk About Your Sorrow.

Take the time to seek comfort from friends who will listen. Let them know you need to talk about your loss. People will understand, although they may not know how to respond. If they change the subject, explain that you need to share your memories and express your sorrow.

Forgive Yourself.

Forgive yourself for all the things you believe you should have said or done. Also forgive yourself for the anger and guilt and embarrassment you may have felt while grieving.

Eat Well and Exercise.

Grief is exhausting. To sustain your energy, be sure to maintain a balanced diet. Exercise is also important in sustaining energy. Find a routine that suits you - perhaps walks or bike rides with friends, or in solitude. Clear your mind and refresh your body.

Indulge Yourself.

Take naps, read a good book, listen to your favorite music, get a manicure, go to a ball game, rent a movie. Do something that is frivolous, distracting and that you personally find comforting.

Prepare for Holidays and Anniversaries.

Many people feel especially "blue" during these periods, and the anniversary date of the death can be especially painful. Even if you think you've progressed, these dates may bring back some of your painful emotions. Make arrangements to be with

friends and family members with whom you are comfortable. Plan activities that give you an opportunity to mark the anniversary.

Get Help.

Bereavement groups can help you recognize your feelings and put them in perspective. They can also help alleviate the feeling that you are alone. The experience of sharing with others who are in a similar situation can be comforting and reassuring. Sometimes, new friendships grow through these groups - even a whole new social network that you did not have before.

There are specialized groups for widowed persons, for parents who have lost a child, for victims of drunken drivers, etc. There are also groups that do not specialize. Check with your local hospice or other bereavement support groups for more information.

If you find that you are in great distress or in long-term depression, individual or group therapy from a counselor who specializes in grief may be advisable. You can ask your doctor for a referral.

Take Active Steps to Create a New Life for Yourself.

Give yourself as much time to grieve as you need. Once you find new energy, begin to look for interesting things to do. Take courses, donate time to a cause you support, meet new people, or even find a new job.

It is often tempting to try to replace the person who has been lost. Whether through adoption, remarriage, or other means; this form of reconciliation often does not work.

Many people discover that there is hope after death. Death takes away, but grief can give back. It is possible to recover from grief with new strengths and a new direction. By acting on our grief, we may eventually find peace and purpose.

Helping Those in Grief

You may know someone who has experienced a loss. Many of us feel awkward when someone dies, and don't know what to do or say. The suggestions below are designed to help you help friends, family and coworkers who are grieving.

Reach Out to the Grieving Person.

Show your interest and share your caring feelings. Saying the wrong thing is better than saying nothing at all. At the same time, avoid clichés like "It was God's will," or "God never gives us more than we can bear", or "At least she isn't suffering." Do not say you know how it feels. Do say you are sorry and that you are available to listen. Be prepared for emotional feelings yourself. A death generates questions and fears about our own mortality.

Listen

Your greatest gift to a grieving person can be your willingness to listen. Ask about the deceased. Allowing the person to talk freely without fear of disapproval helps to create healthy memories. It is an important part of healing. While you can't resolve the grief, listening can help.

Ask How You Can Help.

Taking over a simple task at home or at work is not only helpful, it also offers reassurance that you care. Be specific in your offer to do something and then follow up with action.

Remember Holidays and Anniversaries.

These can be a very difficult time for those who are in grief. Do not allow the person to be isolated. Remember to share your home, yourself, or anything that may be of comfort.

Suggest Activities That You Can Do Together.

Walking, biking or other exercises can be an opportunity to talk, and a good source of energy for a tired body and mind.

Help the Grieving Person Find New Activities and Friends.

Include grieving persons in your life. Grieving people may require some encouragement to get back into social situations. Be persistent, but try not to press them to participate before they are ready.

Pay Attention to Danger Signs.

Signs that the grieving person is in distress might include weight loss, substance abuse, depression, prolonged sleep disorders, physical problems, talk about suicide, and lack of personal hygiene.

Observing these signs may mean the grieving person needs professional help. If you feel this is the case, a suggestion from you (if you feel close enough to the person), or from a trusted friend or family member may be appropriate. You might also want to point out community resources that may be helpful.

Death can be a painful and permanent loss experience, and one of the hardest from which to recover. Death takes away, but facing it and grieving can result in peace, new strengths and purpose.

How do we know when we need hospice?

Patients are eligible for River Region Hospice when it has been determined that there are no longer curative options for their disease or when the risks of treatment outweigh the gains, and their doctor has estimated the patient's life expectancy to be months rather than years. Although nothing can be done to cure the disease, a lot can be done to keep the patient comfortable and enhance their quality of life.

Our patients and families may be dealing with terminal illness but there is still life to be experienced, savored, and enjoyed. Every patient and family has their own idea of what that means to them. Hospice of Holland is here to help make it possible.

The decision to seek Hospice is a reversible one. Patients may discontinue Hospice care at any time.

What can you do for patients with incurable illness?

Hospice care is sometimes called palliative care, from the Latin word *pallium* meaning a cloak. The idea is that, when cure is no longer possible, it

is still very important to patients that their pain or sickness or other problem is met or relieved – or "covered up comfortably" like a cloak does.

Pain:

In practice, the thing most of our patients most dread is pain. So the first priority of hospice care is to relieve pain. There are effective medicines for this purpose, ranging from Paracetamol through a variety of stronger pain-killers to Morphine and other similar medications. Our aim is not only to deal with the pain when it occurs, but to prevent it coming back and so to reduce the memory and fear of the pain.

This means that medicines have to be given regularly, at the right dose and in the right way. For most people that will mean pills or potions, every four hours or so. Sometimes people are unable to take medicines by mouth and so we may use injections, or suppositories (by the back passage).