



Adding Life to Each Day

*Helping Your Loved One
at the End of Life*



IOWA CITY
HOSPICE

not-for-profit

Introduction

The death of someone you love is one of the most difficult experiences you will ever face. Our approach at Iowa City Hospice is to be as open, honest, and compassionate as possible in providing information to help you. This booklet will give you information about the end-of-life process so you can help your loved one accomplish the transition with support, understanding, and ease. This is a gift that you can offer your loved one.

As the end of life approaches, most people slow down gradually. At times, death has been expected for several days, goodbyes have been said, and death is peaceful.

Some people die gradually and some die suddenly; each death is a unique experience for that person. During the final days, weeks, or months of life many changes will occur. All of these are part of a natural series of changes that happen near the end of life. These changes are part of a transition that is unique to each individual; some may experience all of the signs in this booklet while others may have only a few. The process may continue for several months or it may be much faster. When you understand what to expect, you will be better prepared to cope with this transition.

"I am comforted by knowing that Iowa City Hospice is there for them and providing such great care to both my aunt and uncle."

--the niece of an Iowa City Hospice patient

The information here explains how the body prepares itself for

the final stages of life and what physical, emotional, and spiritual symptoms may occur, and what you can do to help care for your loved one. Your Iowa City Hospice team members will be with you every step of the way, and are available to answer any questions you might have about your loved one's care. Please call on us whenever you need to.

What you can do: Remember that you and your family will need to get enough rest and eat regularly to maintain your own health. Caring for a loved one can be very demanding. It is important to take an occasional break and arrange times with others who can relieve you. By caring for yourself you will be better able to provide care for your loved one. Be aware that family members may feel overwhelmed by the physical and emotional stress of caring for a loved one. It may help to discuss your feelings with each other and your Iowa City Hospice team members, especially your Social Worker. Be open and honest with the children in your family. Talk about death when the subject arises naturally, such as when a pet dies. Explain what is happening in a manner that is appropriate for their age. Help them express their feelings and fears, reassure them they will be taken care of, and that the death is not their fault. Let them visit the loved one if they wish.

"We're facing each day with heavy hearts, but are comforted by one everlasting memory. We never would have been able to bring such dignity and grace to his final days without the staff of Iowa City Hospice."

--the wife of an Iowa City Hospice patient

WHAT HAPPENS DURING THE DYING PROCESS

When a loved one enters the final stage of the dying process, there are physical changes, as well as spiritual and emotional changes. Each person is unique and needs to do things in his or her own way, as they always have.

On the physical level, the body begins the final process of slowing down. These physical changes typically progress in an orderly and expected fashion and do not require dramatic medical treatments. The most important thing to do at this point is to make the individual comfortable and pain-free. Your Iowa City Hospice team will be able to do this through a variety of techniques including physical, emotional and spiritual support, medications, and therapies. Always feel welcome to ask your Iowa City Hospice team members if you have questions about how this care is being provided to your loved one.

The spiritual and emotional signs of the dying process are unique to each person and will vary according to their values, beliefs, and lifestyle. The dying person may experience varied and mixed emotions. This is completely normal and expected. Your loved one may find comfort from sources that are important

“Our entire family is so thankful for the services you provided, making it possible for my Dad to stay at home with us. We could not have done it without you, and knowing that someone was there at any time of the day or night made us so much more confident that we could do what Dad needed.”

--the family of an Iowa City Hospice patient

to them such as music, readings, faith practices, or the simple presence of loved ones. At this point you and your loved one may find comfort in the support of your Iowa City Hospice team's Spiritual Counselor or Music Therapist.

Your loved one may begin to withdraw from the world around them and begin to focus inwardly. This is also completely normal. Your loved one may lose interest in the news, activities, or even visits with family and friends. This does not mean that they no longer care, but that their energy is focused on the transition process they are going through. It is very common for your loved one to sleep more and more, to lose interest in food, and to experience other changes. All of these are normal, and there are things you can do, described in each section of this booklet, to help make your loved one comfortable. For some the changes will be very gradual, while for others they will progress quickly. In the final days and hours before death occurs, these changes will become more intense.

"We do not know how to tell you how much you impacted our mother's life in her last six months. The staff and volunteers were so wonderful. She told us every time someone came and what they did. She loved the music and would always ask if they would play for everyone after their lunch, the whole home would sing along, it was not only great for her but it made the other residents smile."

--the family of an Iowa City Hospice patient

Physical Changes

BODY TEMPERATURE

Your loved one's hands, arms, feet and then legs may be increasingly cool to the touch, while at the same time his or her skin color may change. This means that the circulation of blood is decreasing to these areas to be able to supply the most vital organs. It is also possible that your loved one may feel warm or feverish; this is because of an increased metabolism. Some people will alternate between warm and cold.

What you can do: If they are cool, keep your loved one warm with a blanket. An electric blanket is not a good option because a person who is very ill may not be able to tell you if they become overheated. If they are warm, a cool, damp cloth on their forehead or the breeze from a fan can bring comfort.

SLEEPING

Sleeping more often is very common. Perhaps your loved one will begin taking naps at new times, or sleeping longer at night. This is completely normal and may happen more and more frequently with or without medication.

What you can do: Sit with your loved one or hold his or her hand; if touch has provided comfort in the past, it may be very welcome. Plan to spend time with them when they are awake or most alert. Speak softly and normally but keep in mind that even though your loved one may appear to be sleeping they may be able to hear you. Hearing is the last of the senses to be lost.

LOSS OF INTEREST IN FOOD AND FLUIDS

Food is what our bodies need to stay healthy and strong, and meals are a very social activity for friends and families. Watching your

loved one lose interest in food can be very difficult. It's natural that food may become less and less necessary when your loved one is preparing to die. Your loved one's appetite may decrease and eventually they may experience cravings or want only soft foods, fluids, or perhaps nothing at all. This is completely normal and a sign that the body is losing its ability to process food and fluids; encouraging them to eat may cause physical pain and distress.

What you can do: Make food and fluid available, but do not pressure your loved one to eat or drink. This may be difficult for you to accept, but it is important for the well being of your loved one. Small chips of ice or frozen juices may be comforting. You can also keep the inside of the mouth moist with a special little sponge on a stick that is made for this purpose and can be provided by your Iowa City Hospice team. If your loved one wants little or no fluid or food, this may indicate they are ready for the final transition.

"We were blessed to have you with us as we walked together with our mom during the final months of her earthly journey."

--the daughter of an Iowa City Hospice patient

DISORIENTATION

Your loved one may begin to seem confused about time and place, and may not recognize familiar faces. They may also become restless, often making repetitive motions such as pulling on the bed linens or clothing. This is completely normal and occurs for several reasons including decreased oxygen to the brain, chemical changes in the body, and medications.

What you can do: Create a calm atmosphere with music, reading out loud, or hand holding. Identify yourself and visitors by name and speak softly but clearly. Describe what you are doing so you won't startle your loved one. For example, tell them "It is time for your medication, so you won't be in pain."

BREATHING PATTERN CHANGES, RATTLING, AND CONGESTED SOUNDS

These changes typically occur in the final days to a week or two before death. Your loved one may produce gurgling sounds that come from his or her chest and these sounds may become very loud. This sound does not disturb the patient but may be unsettling for you. Some people may have periods of rapid, shallow breathing while others have periods where there are spaces of 5 to 60 seconds between each breath. All of these are normal.

What you can do: Changing your loved one's position can help with any of these breathing patterns. Gently turn your loved one's head to the side to allow gravity to drain the secretions that cause the gurgling and rattling sounds. Turning or elevating the patient's head can also help change breathing patterns. Speak gently and tell your loved one what you are doing, hold their hand, and ask your Iowa City Hospice team members for other ways you may be able to give comfort.

"Your dedicated team provided my father with superior care that was courageous and compassionate. God bless you in your continued service to those who face a terminal diagnosis."

--the family of an Iowa City Hospice patient

CHANGES IN SKIN COLOR

Slowing blood circulation can cause blue, blotchy coloring called "mottling" which may be especially noticeable on the hands, feet, and around the mouth. The underside of the body may also look darker. This is completely normal.

What you can do: Ask your Iowa City Hospice team members whether there are ways you can position your loved one that will help.

BLADDER AND BOWEL CHANGES

Your loved one may no longer be able to control their bladder and bowel as the muscles in those areas begin to relax. When the person is taking in less liquid, the amount of urine decreases and the color becomes much darker. This is completely normal.

What you can do: Ask your Iowa City Hospice nurse about disposable pads and adult briefs that will help to keep your loved one clean and comfortable, and whether a catheter might increase comfort. Your Iowa City Hospice Aide will also be able to provide assistance.

SURGE OF ENERGY

Some people who are close to death will experience a surge of energy and alertness. They may think clearly after having been confused, they may wish to eat after not having had a meal in quite some time, and they may wish to visit and talk with family and friends. This may be a final opportunity for your loved one to be fully present with you.

What you can do: This is an opportunity to express love and support.

“Iowa City Hospice allowed us to be together with our mom during these final months and keep her home until she took her last breath. For the love, the care and the tenderness that was shown to us, we as a family remain eternally grateful.”

--the daughter of an Iowa City Hospice patient

Emotional and Spiritual Changes

WITHDRAWAL

In their final days, many people begin to quietly separate themselves from the world around them. Your loved one may no longer show interest in surroundings, the news, favorite activities, friends or even family. There may be just one or two people your loved one chooses to interact with at this point. This does not mean that he or she is rejecting others. Usually this period of withdrawal is a peaceful time for a person who is dying and is a time for letting go.

What you can do: Talking becomes much less important at this time. Instead, the presence of loved ones and comforting touch are the gifts you can give your loved one. If you are one of the few people with your loved one at this time, he or she needs your support and permission to let go when they are ready.

"I felt as though my mother and I were 'rescued' by the hospice team. They scooped us up from our confusion and despair and said, 'We know what to do, we can help you,' and they did. I will be forever grateful for the peace and comfort that Iowa City Hospice gave to my mother and me."

--the daughter of an Iowa City Hospice patient

VISION-LIKE EXPERIENCES

As your loved one enters their final transition, they may speak to or about someone you cannot see, often loved ones who have already died, or to have seen spiritual beings such as angels, or places that are not visible to you. This is very common and does not indicate a hallucination or reaction to medication. Instead it means that your loved one is beginning to detach from this life and is preparing for the transition. These visions and encounters are very real to your loved one and usually are comforting to them.

“His concern was for peace as he lived his final days, and you helped make that happen.”

--the daughter of an Iowa City Hospice patient

What you can do: Do not contradict, explain away, or argue about what your loved one says they have seen or heard. Just because you cannot see the visions does not mean that they are not real to your loved one.

CHOOSING WHEN TO LET GO

A person near the end of his or her life may continue to be protective of loved ones, and continue to make decisions that are right for them. For some, death is a private act and they will wait for a moment when they are alone to slip away. Some may choose to let go when they are alone with a certain loved one. Others may choose to let go with their full circle of loved ones at their bedside.

What you can do: Trust that your loved one will make the choice that meets his or her own needs. As you decide how much time to spend at the bedside, remember that it is not necessary to push yourself to the point of exhaustion. Breaks are important for you and taking one does not mean that you are not supporting your loved one. Iowa City Hospice can also provide an 11th Hour Volunteer to be with your loved one so that you may rest.

GIVING PERMISSION TO LET GO

A dying person may try to hold on, even in the face of significant discomfort, if he or she is worried whether those left behind will be alright. Giving permission to your loved one to let go, without making him or her feel guilty for leaving or trying to keep him or her with you to meet your own needs, can be difficult. Permission to let go, with assurance that those left behind will be alright, is one of the greatest gifts you can give your loved one at this time.

What you can do: Let your loved one know that you will be alright, that you love them, and will remember the love and affection you shared. Giving permission is a personal matter; share words that are comfortable to you and meaningful to your relationship with this person.

“Iowa City Hospice did a wonderful job of reaching out and staying in touch over the year since my father’s death. Thank you for all the support your staff have provided to me and my siblings.”

--the family of an Iowa City Hospice patient

SAYING GOOD-BYE

When your loved one is ready to die and you are able to let go, then it is time to say good-bye. Saying good-bye is your final gift of love to your loved one. Saying good-bye can be as simple as saying “I love you.” It may include sharing favorite memories, places and activities you shared. It may include saying you are sorry for any tension or difficulties in your relationship. It may also include saying thank you. Hearing is the last sense to shut down, so share important messages with your loved one even if they appear to be unconscious and unable to respond. Tears are natural when we are expressing feelings of love and loss, and you don’t need to hide your tears.

What you can do: Share your feelings of love and support in a soft voice, hold your loved one’s hand, and provide comforting touch. Your Iowa City Hospice team is here to help you through this difficult time.

We, the staff and volunteers of Iowa City Hospice, appreciate the trust you have placed in us to care for you and your loved ones at this time in your lives. Thank you for choosing Iowa City Hospice to provide this care.

How you will know that death has occurred

Being present at the time of death can be a very powerful experience. It is helpful for you to talk to your family in advance about what you will do if you are present at the time of death. The death of a hospice patient is not an emergency and nothing must be done immediately. The signs of death include such things as:

- No heartbeat
- No breathing
- Mouth relaxed and slightly open
- Eyelids slightly open
- Pupils enlarged and eyes fixed on a certain spot
- No blinking

What you can do: Note the time your loved one died and call your Iowa City Hospice team at (800) 897-3052 no matter what day or time it is. If your loved one is in a facility, ask their staff to call us. Your loved one's body does not need to be moved until you are ready, and friends and family may come to say good-bye. Your Iowa City Hospice team will call the funeral home, notify the physician, assist with disposal of medications, and make sure any medical equipment is removed.

We Remember Them

We remember them in the rising moon
We remember them in the mourning dove
When the waters rush upon the shore
We remember them, singing ever more

We remember them in the blowing wind
We remember them in the rustling leaves
When the buds unfurl into the spring
We remember them, and we join to sing

We remember them in the fallen tree
We remember them in the candle flame
When the blue of the sky opens wide
We remember them and keep their songs alive

And they, too, shall live
As they are woven into us.

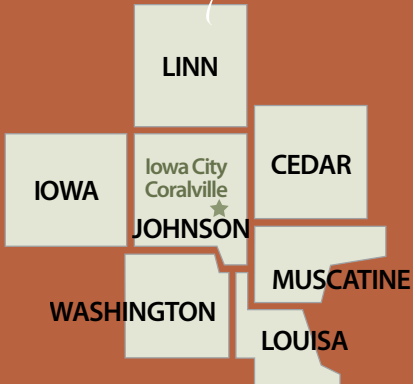
We remember them in the rising moon
We remember them in the mourning dove
When the waters rush upon the shore
We remember them, singing ever more

I remember you singing evermore...

-Music and lyrics by Trish Bruxvoort Colligan
Inspired by the Jewish prayer, *We Remember Them*



Our seven-county service area



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Note: Some of the information provided in this booklet was provided courtesy of Home & Hospice Care of Rhode Island