



HOSPICE OF THE WESTERN RESERVE

The Journey's Path

Caring for your loved one during
the final stages of life's journey.





"What lies behind us and
what lies ahead of us are
tiny matters compared
to what lives within us."

— OLIVER WENDELL HOLMES

We at Hospice of the Western Reserve and Stein Hospice support you in caring for your loved one during the final stages of life's journey. Everyone's life is unique and so is their journey toward death. We realize that this is a difficult time because people may not know what to expect.

We hope this information will help you to be more confident, informed and prepared. Even with this knowledge, it is natural to be confused and unsettled.

Be kind and gentle to yourself.

The Journey's Path provides common experiences of those dying. This booklet explains physical signs and symptoms, as well as some of the emotional and spiritual challenges that may occur during one's final days when death is near.

Months before death, it is not uncommon for the dying person's world to **focus inward**. There is a shift away from the more social world. Perhaps there is inner work to be done. You and your loved one may wonder what the meaning and purpose of life is. This might be a time to ask for forgiveness, express feelings of guilt or lack of trust. This could also be a time to reminisce and share stories, as well as look for closure and resolution.

The following four sentences have been found to ease suffering at the end of one's life:

"Please forgive me!"

"I forgive you!"

"Thank you!"

"I love you!"

With permission from Ira Byock, www.dyingwell.org

These “four things” are about completing relationships and reconciling strained relationships. Completion means that there is nothing left unsaid or undone. While this may be difficult, it often brings peace. This could be a time of openness for you and your loved one. This is also a time when you may feel relief. Your greatest gift to your loved one is just to be present. Listen attentively.

Physical Signs and Symptoms of Approaching Death

You have undertaken the most precious service by caring for a loved one.

As your loved one prepares for the final stage of life, you may notice physical changes taking place. **Not all of these signs will appear at the same time and some may never appear at all.** It may appear as if your loved one is struggling. Your hospice team will help you with these symptoms and changes and support you through this difficult time.

Your loved one will have a **decreased need for food and drink** because the body functions are gradually slowing down. They will not experience hunger as the body has its own wisdom and knows what it needs. There may be **difficulty in swallowing** and the mouth may become dry and will need to be kept moist.

Your loved one will gradually spend more time **sleeping** during the day and at times will be **difficult to arouse**. This symptom is a result of a change in the body's metabolism. Try to spend more time with your loved one during those times of greatest awareness.

Restlessness can be part of the dying process. It is common for a person to become restless and pull at the bed linen. Restlessness does not necessarily mean that pain is present. Your loved one may become increasingly **confused** about time, place and the identity of close and familiar people. Offer reassurance. Reminders as to what day it is, what time it is, and who is in the room will be comforting. Soft music and dim lights may be calming. Keep the side rails up for safety. Again, your presence, just being near, is very important.

"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart."

—Helen Keller

Incontinence (loss of control) of urine and bowel movements may occur. Your hospice nurse or nursing assistant can help you obtain pads to place under your loved one for more comfort. You may notice a **decrease in the amount** of urine and it will be **darker** in color. This is to be expected as the kidneys and intestinal system begin to slow down.

Your loved one may have **moist-sounding breathing**. Relaxed vocal cords and a small amount of oral secretions collecting in the back of the throat cause this. Your loved one does not feel any discomfort from this and may not even be aware of it. Elevating the head of the bed or turning your loved one on their side will usually quiet the breathing sounds. There may be periods of time when the breathing sounds labored. While this may be stressful to you, feel assured that your loved one is comfortable.

You may notice a **change in breathing patterns**. There may be 10–30 second periods of no breathing, referred to as apnea. This symptom is very common and may occur in the final stage of life.

Clarity of **hearing and vision may change**. Keep some soft light on in the room. Assume that your loved one can hear, since hearing is thought to be the last of the senses to diminish. Explain what you are doing.

At the very end your loved one will be unable to respond to touch or voice. Continue to speak to your loved one. The soothing sound of your voice and your words may be a source of comfort.

Pain and discomfort *can be* controlled as death approaches. Also, your loved one *may not appear* to be in pain. There may be **moaning sounds**, which may not necessarily signify pain. To insure effective pain management, continue to give medications as directed by the nurse.

Your loved one's **arms and legs may become cool to the touch and bluish** in color. There also may be **mottling** (reddish blue blotches) which starts on the underside of the feet and progresses toward the knees. You may notice that the underside of the body is somewhat darker in color. These physical signs are a result of blood circulation slowing down and do not necessarily indicate that the person is too cold. **Fevers** may occur as well.

Nearing Death Awareness

In the final hours, days, or weeks, your loved one may make statements or gestures that seem to make no sense. Your loved one may have **visions** of people and things you cannot see. **Nearing Death Awareness** often includes visions of loved ones or spiritual beings. This visioning is often comforting. Your loved one may use **metaphors**, such as preparing to go on a trip or journey. Keep an open mind and listen carefully to underlying messages. You may find these messages very comforting.

Use the personal reflection page at the end of the booklet to record your loved one's comments.

Saying Goodbye Emotional Challenges

Everyone reacts to the dying process in his or her own way. There are some common emotions that you, as the caregiver, may experience. Although you may often feel overwhelmed, remind yourself that what you are going through is normal. Remember to take some time for yourself.

Grief

Grieving plays an active role in the dying process. Grief is as unique as a fingerprint. Grief has no calendar and no timetable. You may have feelings of denial, anger, guilt, fear, abandonment, and confusion.

Reach out to others. Find healthy ways to express your grief and share your feelings. Hospice staff, including the bereavement coordinator, is available for support and assistance.

Deep Sadness

Feelings of sadness and despair may seem overwhelming and uncontrollable. These are natural responses to the dying process. Symptoms of grief and depression can be similar. Grief is normal, but depression can become serious. Signs of more severe depression include losing interest in the people and activities around you, displaying few emotional reactions, or having thoughts of suicide. If you feel that you might be depressed, see your healthcare provider. Thoughts of hurting yourself or others require urgent attention. Contact a member of your hospice team immediately if you have these thoughts.

Uneasy Feelings

Anxious feelings and worries often intrude on thoughts and sleep time. Share your worries with the hospice team members. Often they can provide the information and/or reassurance that you need. They have experienced this with many other families, and their goal is to listen.

As a caregiver, listen to your intuition or inner voice. Do not feel guilty if you need to leave your loved one for a time. Love, itself, cannot be separated.

At the Time of Death

If a hospice team member is not present, call and someone will come to the bedside. There may be differences in how family members respond. Some may wish to have private time with their loved one. Some may wish to provide personal care. The hospice team will support you in your wishes and help you do what feels right for you.

After Death

We know that this is a profound experience for you and your loved one. Hospice is here to support you as you adjust. We are available to you for several months as you move along grief's journey. Remember there is no one formula for grief. After death, Hospice of the Western Reserve will be contacting you to provide support, encouragement, education and resources.

Providing care, presence and love is the greatest gift we can give to each other.



OUR MISSION

Hospice of the Western Reserve provides palliative and end-of-life care, caregiver support, and bereavement services throughout Northern Ohio.

In celebration of the individual worth of each life, we strive to relieve suffering, enhance comfort, promote quality of life, foster choice in end-of-life care, and support effective grieving.

Serving the Northern Ohio Counties of Ashtabula, Cuyahoga, Erie, Geauga, Huron, Lake, Lorain, Medina, Ottawa, Portage, Sandusky, Seneca, Stark, Summit and Wayne.

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Call 216.383.6688.

