

SHARING THE JOURNEY

Comfort and dignity at end of life



HOSPICE
of the **VALLEY**

A legacy of caring since 1977

Sharing the Journey: Comfort and dignity at end of life

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Hospice of the Valley guides patients and families through the end of life with support, comfort and information.

Though birth and death are universal experiences, many people do not know what to expect. This booklet provides information to help you prepare for the death of a loved one. It includes physical symptoms and changes that are likely to occur, but may never appear. As each life is unique, so is each death.

Please consult your Hospice of the Valley team as questions arise. Together, we will share the journey.

In the depth of your hopes and desires,
lies your silent knowledge of the beyond;
And like seeds dreaming beneath the snow,
your heart dreams of spring.

— from The Prophet, Kahlil Gibran

ONE TO THREE MONTHS PRIOR TO DEATH

The actual physical process of dying often starts two weeks prior to death, but changes occur in the preceding months as the person reflects on end of life and belief systems about what happens next.

Your loved one may withdraw and begin to separate from the world around them. The person may sleep more as the body slows down, spending most of the day in bed. It is normal to need more rest. While asleep, the person may be mentally reviewing important life experiences and relationships.

When your loved one is alert and awake, lend your presence. Having people nearby, even just sitting quietly in the room, usually affords comfort and reassurance. Touch becomes more important than words. Hold hands. Play or sing music the person enjoys.

Food is a natural way to nurture others. When someone is sick, we urge the person to eat, but the dying person loses interest in eating and drinking as the body gradually shuts down. Food becomes unappetizing, especially meat, vegetables and hard-to-digest foods. Soft foods like pudding or ice cream are preferred.

It may be difficult for you, but sometimes your loved one may not want to eat or drink anything. It also isn't unusual for a very ill person to ask for particular foods, only to refuse them when they arrive. Do not take these upsets personally. Keep portions small and continue to offer foods that you think could be appealing. If food or drink is refused, it is okay.



If your loved one is confused about time, place and the identity of people, don't be alarmed. Answer questions calmly. Say your name when you address the person, and describe what you are going to do before you do it. If the person becomes intensely worried or excitable, your hospice team can help.

ONE TO TWO WEEKS PRIOR TO DEATH

As your loved one begins separating from the physical world, restlessness and confusion may set in. The person may pull at the bed linen, talk with loved ones who have died before them, or describe taking a symbolic trip "home." Much of the time, the person is asleep. Be present, open, and loving, offering reassurance.

The physical body undergoes changes. The blood pressure lowers. The pulse rate may alternate between fast and slow. Body temperature may rise, then decline. As blood circulation slows, arms and legs become cool to the touch. The skin appearance on the underside of the body may become dark or blotchy. The face may appear drawn or waxy, or increase in pallor. Nail beds may appear pale or blue. Perspiration increases. The patient may want a light blanket, but kick off heavy covers. Hearing is the last of the five senses to be lost, so never say anything you would not want the patient to hear, even if the person appears asleep.

Breathing becomes irregular. The person may breathe rapidly, very slowly, or stop breathing for brief periods, only to resume again. There could be a puffing or blowing upon exhaling. As fluids build up in the lungs and upper throat, there may be rattling sounds or coughing, but nothing can be brought up. This can be distressing to hear, but is not painful to the patient. Most often, nothing needs to be done. Helping the person lie on his or her side, or elevating the head with pillows may help. This pattern may exist for days, coming and going.

ONE TO TWO DAYS OR HOURS PRIOR TO DEATH

Some people experience a surge of energy within days or hours of death. The person may sit up, speak clearly with loved ones, or eat a meal. This is a blessed opportunity for the family and patient to express their feelings to one another. It is not unusual for such periods to be followed by the person falling into a deep sleep.

Touch, hold and comfort one another. Maintain an environment that the person likes — TV on or off; music they like or silence; photos of loved ones displayed on the walls; a favorite bed covering or stuffed animal; religious or spiritual symbols; and prayers or rituals that are meaningful. A hand and foot massage, with or without lotion, may be relaxing and pleasurable.

Incontinence (loss of control) of urine and bowel movements is usually not a problem until just before death. Sometimes it does not happen. Your nurse or nurse's aide can give you pads to place beneath your loved one. If a catheter is in place, you may notice a decrease in urine and change in color.

The signs that were present earlier may become more pronounced, with irregular or noisy breathing. Hands and feet become purplish, and the body's underside can become blotchy. Eyes may be glassy, not seeing. Usually the person is unable to respond to their environment.

Signs of death

- No breathing. (There will be no condensation on a mirror held in front of the nose or mouth.)
- No heartbeat, no blood pressure. (No pulse.)
- No response to verbal commands or touch.
- Jaw relaxed and mouth slightly open.

Next steps after death

- Call your Hospice of the Valley office. A staff member will come to your home, if you wish, and notify the doctor and mortuary you have selected.
- There is no need to call 911 or have your loved one declared dead, since this is an expected event in hospice.
- The mortuary will arrive at your home in a van. Attendants will bring a stretcher inside and place the body on it with a covering. You may help if you wish or stay in another room. The attendants will take the body to the mortuary.
- At this point, you are likely to feel a rush of emotions — shock, sorrow, guilt, relief, anger and denial. Even though the death was expected, it may be hard to believe the reality. Allow yourself to express your feelings as you embark on the path toward healing.

HOW LONG? HOW TO KNOW?

Many things can influence how long a person lives with a terminal illness. People die suddenly from unexpected causes, or they live longer than anyone expected. We don't know why.

General guidelines that may be helpful

As your loved one declines, becomes weaker, eating less, spends more time in bed, pay attention to the length of the decline.

- Are you seeing increased changes over a month? Then your loved one may have months to live.
- Are you seeing increased changes over a week? Then your loved one may have weeks to live.
- Are you seeing increased changes over a day? Then your loved one may have days to live.
- Are you seeing increased changes over an hour? Then your loved one may have hours or less to live.

GENERAL TIME LINES, CHANGES AND ACTIVITIES

1–3 Months

- Withdrawal from the world
- Spends more time sleeping or in bed
- Eats less
- May become confused at times

1–2 Weeks

- More restless
- Talks with the “unseen” or deceased loved ones
- More confused
- More sleeping
- Changes in heart rate and blood pressure
- Changes in skin color and temperature
- Changes in breathing



Days or hours

- May have a surge of energy followed by deep sleep
- May have loss of urine and bowel control
- Greater changes in breathing, skin color, heart rate
- Does not respond

THE FOUR GIFTS

People often wonder what to say to their loved one as the end of life draws near. In *The Four Things That Matter Most: A Book About Living*, Dr. Ira Byock, an international leader in hospice and palliative care, shares four expressions that can bring healing shifts in relationships and open the door to more honest communication. These four simple phrases — “Please forgive me; I forgive you,” “Thank you,” “I love you,” and “Farewell” — carry enormous power.

Forgiveness (“Please forgive me; I forgive you.”)

The first step is to acknowledge that another person has hurt or disappointed us, or that we have caused hurt to that person. The intention is to release the hurt. Forgiving does not condone or accept a serious wrong. It does not depend on the other person giving forgiveness, although this can bring reconciliation. What it does is release the heart from the burden of resentment. This step may take rehearsing and practice, as we may feel awkward, uncomfortable or vulnerable. It is the gateway to the other Gifts.

Love (“I love you”)

Using these words may not be habitual in some families, but most people secretly long to hear them. It is meaningful to include memories and stories of shared experiences, as well as to identify the values, attitudes and beliefs unique to the other person. Ultimately, the message is that we are each loved for being just who we are and just for being.

Gratitude (“Thank you”)

Take time to thank each other for what we have been in each other’s lives. Look back and remember the good and hard times. Use photographs, music and stories to convey appreciation and be sure to thank each other for what we often take for granted about ourselves, like cooking meals or going to work.

Farewell (“Goodbye, I’ll be all right”)

Many people say they hate goodbyes, yet if the opportunity is missed they may regret it and feel incomplete. When the time is right, saying farewell in whatever words feel right can convey a reassuring message that the relationship is deeply valued and that the inevitable is being faced. Some phrases people have used are: “I know the time will come when we’ll have to part, and these are some of my feelings and thoughts...”; “I hate thinking about having to go on without you, yet I want you to know I am going to make it.” Allowing painful emotions to flow can bring relief and greater closeness. It is a natural and healthy way that helps people heal the pain of loss and find the energy to take the next step.

BEREAVEMENT

When your loved one dies, your world changes profoundly. Grieving is the process of mourning the loss and adjusting to the changes. Grief is painful and healing is gradual. Feeling fragile is not a sign of weakness. Feeling lonely does not mean you are alone.

Everyone deals with grief differently, with varying degrees of intensity. You may have physical symptoms, like fatigue, difficulty sleeping, or trouble fighting off colds or other viruses. Periods of confusion and forgetfulness are normal, as are experiences of speaking with, “seeing,” or sensing your loved one. You may feel numb, have dreams about the person who died, forget that the person is gone, have difficulty making decisions, or lose interest in things.

These symptoms and feelings are normal, and will come and go over the weeks and months following the loss. Working through pain is part of the process. As much as you can, allow it to happen. Above all, be easy on yourself. Eat nutritious foods, rest and exercise. Respect your needs to be alone, to keep busy at times and to lean on family and friends for practical and emotional support.

Hospice of the Valley offers bereavement support through the first year following the death at no cost to you. This includes written materials, ongoing, no-fee support groups, and brief one-on-one counseling by professional grief counselors. In addition to general grief support groups that meet regularly, short-term focused groups and remembrances are offered.

Within the first two weeks, a packet of helpful information will be sent to you. You may also visit hov.org/our-care/grief-support for announcements and other timely information and resources. Please feel free to call our Bereavement Department at (602) 530-6970.

Gone From My Sight

by Henry Van Dyke

I am standing upon the seashore.

A ship, at my side, spreads her white sails to the moving breeze
and starts for the blue ocean. She is an object of beauty and strength.

I stand and watch her until, at length, she hangs like a speck of white
cloud just where the sea and sky come to mingle with each other.

Then, someone at my side says, "There, she is gone."

Gone where?

Gone from my sight. That is all.

She is just as large in mast, hull and spar as she was when she left my side.
And, she is just as able to bear her load of living freight to her destined port.

Her diminished size is in me — not in her.

And, just at the moment when someone says, "There, she is gone,"
there are other eyes watching her coming,
and other voices ready to take up the glad shout, "Here she comes!"

And that is dying...



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