



May I Go?



EverHeart
HOSPICE

Honoring life with trusted care

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Dying is an experience unique to each person.

This booklet is only a guideline. Nothing is written in stone. Each person's death comes in its own way and in its own time. Many of the changes you will read about in this booklet may be present, some may occur or none may occur. Think of it as many streams from different directions heading towards the same destination. Each person's dying experience is as unique as the individual.



The Dying Process

Many physical and emotional changes occur during the dying process which can be disturbing for the person dying and also for the families and caregivers. Being aware of what to expect and why certain things are happening can be helpful during these difficult times. Usually the dying process occurs over a period of time. Initially, a person may be able to perform most activities independently. As their disease progresses, they become more dependent on caregivers and family members for assistance.

Physical Changes

FOOD AND FLUIDS

The body's metabolism slows as the disease progresses; energy levels and appetite are dramatically reduced. This can be a cause of frustration for the dying person and their family. The dying person is physically unable to tolerate food and fluids as they had before their illness. They also become too tired and weak to eat.

As appetite decreases, many things occur. Dehydration begins and this causes sleepiness and acts as a natural analgesic (pain reliever). This effect can be helpful in the dying process. Protein levels drop so fluids can leak into the tissue causing swelling and discomfort. Large amounts of fluids can be uncomfortable and are usually not helpful at this point.

THINGS YOU CAN DO

- › Don't take it personally when your loved one doesn't want to eat the food you have prepared. Remember, their bodies are changing and it takes too much energy to eat or drink.
- › Offer food and fluids in small amounts frequently throughout the day, and if they refuse, do not force them to eat or drink. Remember, swallowing can become difficult and choking may occur more easily than normal.
- › Small amounts of cool or cold liquids like ice chips, frozen Gatorade, or juice can be refreshing and easy to swallow. At this point, you may have to begin giving them their pills in applesauce or pudding for easier swallowing.
- › Keep their mouth moist with lip balm, liquid saliva, and a small spray bottle filled with cool water. Your hospice nurse will assist you with selecting a moistener.

INCREASED SLEEP, CONFUSION, AND RESTLESSNESS

Because of a decreased intake of food and fluids, dehydration and sleepiness may occur. As their disease progresses, the person may spend an increasing amount of time sleeping, seem to be less talkative, may become more difficult to awaken and eventually become unresponsive. Many things are happening to cause these changes. Electrolytes (elements in the blood) and blood sugar levels may change which can cause confusion and restlessness. Kidney and liver function may decrease or may even shut down causing toxins and ammonia levels to rise. This may also add to the confusion, restlessness, and sleepiness.

If the person has cancer and it has spread to the bone, calcium levels may be high leading to mental confusion. The growing and spreading of cancer tumors can cause organ failure. As the disease progresses, their blood pressure may decrease, heart rate may increase, and a fever may develop. These changes all cause tiredness and weakness. It may be difficult for the person to carry on a conversation without falling asleep. As the body continues to shut down, blood is moved away from the arms, legs and the brain to the most important organ, the heart. Usually at this point, unresponsiveness occurs.

THINGS YOU CAN DO

- › Sit with your loved one, hold their hand, do not shake or attempt to wake up continually.
- › Don't assume that the person cannot hear. Hearing may be the last of the senses to be lost.
- › Identify yourself by name before you speak.
- › Speak softly, clearly, and truthfully.
- › Explain everything you do precisely.
- › If restlessness occurs, do not try to interfere with or try to restrain such motions. Try to stay calm, speak in a quiet, natural way, lightly massage the forehead, read to them or play soothing music. Medications may be necessary. Your doctor and hospice nurse will help with ensuring that appropriate medications are available.

SKIN CHANGES

As the person becomes weaker and spends more time in bed, you may notice skin changes. Skin breakdown may occur. Do not think you are to blame. Remember, a person needs proper nutrition and hydration to keep skin from breaking down and this is difficult to do when food and fluid are causing more harm than good. There is usually weight loss and bony areas may be noticeable through the skin. There is no longer a rich blood supply throughout the body, so skin may often breakdown even with the best of care. Your doctor, hospice nurse, and hospice aide will assist with preventing and treating skin breakdown as best as possible.

As the disease progresses, a person's hands, arms, feet and legs may become cool to the touch. The color of the skin may change. You may see purple blotchiness starting on the feet and hands, then progressing up the legs and entire body. The blood pressure often lowers and the pulse rate may increase or decrease. The body temperature may vary between hot and cold spells. There may be increased sweating and clamminess of the skin.

THINGS YOU CAN DO

- › Keep the person warm with blankets. Do not use an electric blanket.
- › Extra covers, socks, or slippers may help during cold spells. Do not use heating pads because they could burn fragile skin.
- › If feverish, remove blankets and sponge with tepid (not cold/ not hot) water.
- › Easily changed cotton nightshirts or hospital gowns are helpful. A terry cloth towel under the head will absorb perspiration and prevent chilling.



URINE DECREASE AND INCONTINENCE

Because of decreased fluid intake, the person's urine output will naturally decrease. The urine may become concentrated and "tea" colored. The person may also lose control of urine and bowel function as the muscles in that area begin to relax.

THINGS YOU CAN DO

- › Discuss with your hospice nurse and hospice aide what can be done to keep your loved one as clean as possible.
- › Also discuss with your hospice nurse the need for a catheter in the bladder to control incontinence of urine and prevent skin breakdown.

BREATHING PATTERN CHANGES AND LUNG CONGESTION

As terminal illnesses worsen, especially with lung cancers and chronic lung diseases, breathing can become more difficult and a person can become more short of breath. The person's regular breathing pattern may change. For example, the pattern of breathing may become slower and irregular or the person may experience shallow breathing. There may be periods of no breathing lasting anywhere from five seconds up to sixty seconds before breathing begins again. This is called apnea, an episode of no breathing. These patterns are common in the dying process and this means there is a major decrease in circulation in the internal organs.

The person may develop gurgling sounds or rattling coming from the chest. These sounds may become loud. This is usually not distressing to the dying person but may be distressing to the family. At this point, the dying person is unable to cough up secretions due to weakness and their body is in the final stages of dying.

THINGS YOU CAN DO

- › Stay calm.
- › Gently turn the patient to their side to allow gravity to drain the secretions and better open their airway.
- › Gently wipe their mouth with a soft cloth.
- › If the person is trying to cough up secretions, you can help by elevating the height of the head of the bed and supporting the person's head with pillows.
- › The hospice nurse will discuss medications to help with excess secretions and shortness of breath.

Emotional/Physical/Mental Changes

As a person realizes, “yes, I am dying,” the process of withdrawal may occur. Withdrawing, first from the world (newspaper, television, etc.), then from visitors and finally even from the people closest to them: family. Staying in bed and sleeping more becomes normal routine. Realize your loved one still loves you but may be devoting lots of time and energy to the important work of reviewing his or her life.

THINGS YOU CAN DO

- › You know your loved one better than anyone else. If you know they like music, play music softly for them. If they have always enjoyed having and hearing people around them, then place their bed in an area of the home where they can hear, enjoy and participate as much as possible with the daily routine of the household.
- › If you think they may want to talk about what they are experiencing, ask questions such as: Are you worried about anything?, Are you afraid of what is happening to you?, or Would you like to talk about what is going on?

For many people, it is very important for them to know that they have had a productive life and have made an impact on the lives of the people around them.

The dying process takes away a person’s “personhood.” Personhood is who they are, what they have done in their lives, their personalities, their likes and dislikes. It is what makes them feel needed and valuable.

There are times when the dying person and/or family members simply do not want to talk about what is happening to them. They may become angry or agitated when people approach the subject of death or dying with them. It is very important to respect how a person chooses to die. The dying person is

running the show and denial can be a way of coping. It is also very important for the hospice staff to be honest with patients and families. The hospice nurse will discuss their assessment findings with the patient and family with each visit. If the nurse sees that the patient's disease is progressing rapidly, they will gently discuss what is happening. Hospice staff will not dash hopes for a miracle and will offer encouragement and support. There may be a time when the hospice staff may need to assist with moving the dying person's and family's goal from a physical healing to a goal for a meaningful and peaceful death.

THINGS YOU CAN DO

- › Talk to them about all of the positive things they have helped you with and taught you.
- › Life review: Discuss the important events in their lives and the circumstances and the people involved.
- › Look at pictures of the past and present; reminisce.
- › If relationships weren't always good with family members, this may be the time to attempt to mend those relationships.
- › There are times when it is extremely difficult or not even possible or appropriate to fix past relationships and problems. Offer reassurance by listening to them and by your supportive presence. Our social workers and chaplains are available to assist and offer support during this time.

SPIRITUAL/VISION-LIKE EXPERIENCES/RESTLESSNESS

We find that there is a spiritual process happening. The patient often talks to people, and about places and events from the past. They may see and talk with loved ones who have died before them and have vivid dreams or visions. As your loved one moves towards dying, the focus is changing from this world. The person is beginning to detach from this life and preparing for the transition. They may perform repetitive and restless tasks. This may be because something is unresolved or because there is unfinished business preventing them from letting go. There may be picking of bedclothes and agitated arm movements. Sometimes the greatest restlessness occurs at night, and then caregivers lose sleep also. This can be a very difficult time.

THINGS YOU CAN DO

- › Stay calm and speak slowly in a reassuring voice.
- › Ask questions about the dreams and visions.
- › Play soft music or read something comforting.
- › Give reassurance that it is OK to let go.
- › Your hospice nurse may need to discuss medications to help calm the patient.
- › You, the caregiver, may want to nap during the day so that you do not become exhausted. If possible, family members can take turns being awake with the patient.

UNUSUAL COMMUNICATION

Your loved one may make a seemingly “out of character” gesture or request. This shows that they may be ready to say goodbye and is testing to see if you are ready to let them go.

WHAT YOU CAN DO

Accept the moment as a beautiful gift when it is offered. Kiss, hug, cry and say whatever you most need to say.

GIVING PERMISSION/SAYING GOODBYE

Start “giving permission.” Giving permission to your loved one to go, without making them feel guilty for leaving, can be difficult. A dying person will normally try to hold on, even though it brings prolonged discomfort, in order to be sure that those who are going to be left behind will be alright. Therefore, your ability to release the dying person whenever they are ready is one of the greatest gifts you have to give your loved one at this time.

WHAT YOU CAN DO

- › It may be helpful to lie beside the person and hold them, or take their hand and then say everything you need to say.
- › It may be as simple as saying, “I love you.” It may include recounting favorite memories you shared. It may include saying, “I’m sorry for whatever...” It may also include saying, “Thank you for...”
- › Tears are a normal and natural part of saying goodbye. Tears express your love and help you cope with the loss.

How do you know when death is close?

The person will likely display the following:

- › Inability to respond to the outside environment. It is important to keep talking to them, as the ability to hear remains. Tell the person that they are loved and will be missed and that it is okay to go.
- › The eyes may be semi-open but not seeing. There may be a glassy and far-away look to them.
- › The hands, feet, knees, and elbows become purple and blotchy as the circulation slows. This is called mottling.
- › Lung congestion can be loud. It can be lessened by positioning to one side or the other. The congestion is not distressful for the dying person, but may be upsetting to the family or caregivers. There are also medications that can be helpful to dry up secretions causing the congestion.
- › Breathing patterns become slower and more irregular. Breathing often stops for ten to fifteen seconds or even longer before resuming again. This lapse in breathing is called apnea.

How do you know when death has occurred?

The death of a hospice patient is not an emergency. Nothing must be done immediately. The signs of death include such things as: no breathing, no heartbeat, release of bowel and bladder, no response, eyelids slightly open, pupils enlarged, eyes fixed on a certain spot, jaw relaxed and mouth slightly open.

A hospice nurse will come to assist you when death seems closer. Often your hospice nurse is in more frequent contact as signs of approaching death begin to occur. In the event that death occurs and your hospice nurse is not already present, call hospice first. The hospice nurse will make a home visit to verify that death has occurred. The nurse will assist you by notifying your physician and calling the funeral home when you are ready. The police and/or the Rescue Unit or Emergency Squad do not need to be called. The coroner does not need to be called. Also, your loved one's body does not have to be moved until you are ready. If the family wants to assist in preparing the body by bathing or dressing, they may assist the nurse or the aide.

It is very important that the dying person's symptoms remain under control throughout their hospice stay. The hospice nurse will contact your physician for medication for pain, shortness of breath, anxiety, restlessness, sleeplessness, and depression and any other problems that arise during the course of care. Our social workers, chaplains, music therapists, volunteers, and hospice aides are all part of our team to assist with caring for the patient's and family's physical, emotional, and spiritual needs. Our bereavement coordinator is helpful in dealing with the family and caregiver's losses.

The Mourner's Code: 10 inalienable rights as you journey through grief

- 1. *You have the right to experience your own unique grief.*** No one else will grieve in exactly the same way you do. So, when you turn to others for help, don't allow them to tell you what you should or should not be feeling.
- 2. *You have the right to talk about your grief.*** Talking about your grief will help you heal. Seek out others who will allow you to talk as much as you want, as often as you want, about your grief. If at times you don't feel like talking, you also have the right to be silent.
- 3. *You have the right to feel a multitude of emotions.*** Confusion, disorientation, fear, guilt and relief are just a few of the emotions you might feel as part of your grief journey. Others may try to tell you that feeling angry, for example, is wrong. Don't take these judgmental responses to heart. Instead, find listeners who will accept your feelings without condition.
- 4. *You have the right to be tolerant of your physical and emotional limits.*** Your feelings of loss and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. And don't allow others to push you into doing things you don't feel ready to do.
- 5. *You have the right to experience "griefbursts."*** Sometimes, out of nowhere, a powerful surge of grief may overcome you. This can be frightening, but it is normal and natural. Find someone who understands and will let you talk it out.

6. *You have the right to make use of ritual.* The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. More importantly, the funeral is a way for you to mourn. If others tell you the funeral or other rituals such as these are silly or unnecessary, don't listen.
7. *You have the right to embrace your spirituality.* If faith is a part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you feel angry at God, find someone to talk with who won't be critical of your feelings of hurt and abandonment.
8. *You have the right to search for meaning.* You may find yourself asking, "Why did he or she die? Why this way? Why now?" Some of your questions may have answers, but some may not. Watch out for the cliched responses some people may give you. Comments like, "It was God's will" or "Think of what you still have to be thankful for" are not helpful and you do not have to accept them.
9. *You have the right to treasure your memories.* Memories are one of the best legacies that exist after the death of someone loved. You will always remember. Instead of ignoring your memories, find others with whom you can share them.
10. *You have the right to move toward your grief and heal.* Reconciling your grief will not happen quickly. Remember, grief is best experienced in "doses." Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you or those around you must forget that the death of someone loved changes your life forever.

Source: *Journey Through Grief*, Alan D. Wolfelt, Ph.D., Companion Press 2003

How can you help yourself?

These suggestions are stepping stones for your walk through grief:

- › Learn as much as you can about the normal cycle of grief so that you will allow yourself sufficient time to let your grieving take its natural course. Insist that others allow you this time as well.
- › Listen to your heart and find your own way; another person's plan may not work for you.
- › Schedule a health checkup for yourself with your physician.
- › Reorganize your life according to what you NOW feel is important. Examine your values and priorities and make your own decisions with confidence. (It is usually recommended that you postpone major decisions for six to twelve months following the loss of your loved one.)
- › Take care of legal and financial matters and, when necessary, revamp plans for your future.
- › Work to overcome boredom and self-pity. Try to break the old 24 hours routine. Make your idle alone-time an enjoyable, profitable pursuit with hobbies and interests you enjoy. Give yourself a daily goal to work toward.
- › Do not isolate yourself. Talking with others is a prime outlet for grief. Reach out for a hand to hold to help you get back on your feet. You may be surprised to find how many people will support you.
- › Participate in life; attend a movie, have dinner out, go to a sporting event, travel, go to church, join a group or take a course at school.
- › Forget about becoming your "old self " again. Confidence, hope, and faith in yourself will make you capable of living normally again, but you will never be the same.

- › Learn to accept people as they are and not as you would like them to be.
- › Indulge yourself in ways that are emotionally, spiritually and physically healthy. Allow yourself little luxuries.
- › Rather than yearning for the past, think ahead to the promise of the future. Your loved one would have wanted you to stay active in life.
- › Share your strength, faith, hope and experience with others who are still struggling with their grief.

We at EverHeart Hospice thank you for the privilege of assisting you with the care of your loved one.

We salute you for all you have done to surround your loved one with understanding care, to provide your loved one with comfort and calm, and to enable your loved one to leave this world with a special sense of peace and love. You have given your loved one one of the most wonderful, beautiful and sensitive gifts we humans are capable of, and in giving that gift, you have given yourself a wonderful gift as well.

May I Go?

May I go now?
Do you think the time is right?
May I say goodbye to pain filled days
and endless lonely nights?
I've lived my life and done my best,
an example tried to be.
So can I take that step beyond
and set my spirit free?
I didn't want to go at first.
I fought with all my might.
But something seems to draw me now
to a warm and loving light.
I want to go.
I really do.
It's difficult to stay.
But I will try as best I can
to live just one more day.
To give you time to care for me
and share your love and fears.
I know you're sad and afraid,
because I see your tears.
I'll not be far,
I promise that, and hope you'll always know
that my spirit will be close to you,
wherever you may go.
Thank you so for loving me.
You know I love you too,
that's why it's hard to say goodbye
and end this life with you.
So hold me now, just one more time
and let me hear you say,
because you care so much for me,
you'll let me go away.

BY SUSAN A. JACKSON



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