

SLEEPING: The person may spend an increasing amount of time sleeping and appear to be uncommunicative or unresponsive, and at times be difficult to arouse. This normal change is due in part to changes in the metabolism of the body. Sit with your loved one, hold her/his hand, do not shake or speak loudly, but speak softly and naturally. Plan to spend time with her/him during those times when she/he seems most alert and awake.

Do not talk about the person in the person's presence. Speak to her or him directly as you normally would, even though there may be no response. Never assume the person cannot hear; hearing is the last of the senses to be lost.

DISORIENTATION: The person may seem to be confused about the time, place and identity of people surrounding her/him, including close and familiar people. This is also due in part to the metabolism changes. Identify yourself by name before you speak, rather than have the person guess who you are.

Speak softly, clearly and truthfully when you need to communicate something important for the patient's comfort, such as, "It's time to take your medication." Explain the reason for the communication, such as, "So you won't begin to hurt." Do not use this method to try to manipulate the patient to meet your needs. An example would be trying to coax your loved one into making the disorientation go away, such as, "You remember what I told you yesterday, don't you?"

INCONTINENCE: The person may lose control of urine and/or bowel matter as the muscles in that area begin to relax. Discuss with your hospice nurse what can be done to protect the bed, and keep your loved one clean and comfortable.

CONGESTION: The person may have gurgling sounds coming from her/his chest as though marbles were rolling around inside; these sounds may become very loud. This normal change is due to the decrease of fluid intake and an inability to cough up normal secretions. Suctioning usually only increases the secretions and causes sharp discomfort. Gently turn the person's head to the side and allow gravity to drain the secretions. You may also gently wipe the mouth with a moist cloth. The sound of the congestion does not indicate the onset of severe or new pain.

RESTLESSNESS: The person may make restless and repetitive motions, such as pulling at bed linen or clothing. This often happens and is due in part to the decrease in oxygen circulation to the brain and to metabolism changes. Do not interfere with or try to restrain such motions. To have a calming effect, in a quiet, natural way, lightly massage the forehead, read to the person, or play some soothing music.

FLUID AND FOOD DECREASE: The person may have a decrease in appetite and thirst, wanting little or no food or fluid. The body will naturally begin to conserve energy which is expended on these tasks. Do not try to force food or drink into the person, or try to use guilt to manipulate them into eating or drinking something. To do this only makes the person more uncomfortable. Small chips of ice, frozen Gatorade or juice may be refreshing in the mouth. If the person is able to swallow, fluids may be given in small amounts by syringe (ask the hospice nurse for guidelines). A cool, moist washcloth on the forehead may also increase physical comfort.

URINE DECREASE: The person's urine output normally decreases and may become tea colored—referred to as concentrated urine. This is due to the decreased fluid intake, as well as decrease in circulation through the kidneys. Consult with your hospice nurse to determine whether there may be a need to insert or irrigate a catheter.

BREATHING CHANGE: The person's regular breathing pattern may change with the onset of a different breathing pace. A particular pattern consists of breathing irregularly, i.e. shallow breath with a period of not breathing of 5 to 30 seconds and up to a full minute. This is called Cheyne-Stokes breathing. The person may also experience periods of rapid shallow pant-like breathing. These patterns are very common and indicate decrease in circulation in the internal organs. Elevating the head and/or turning the person on his/her side may bring comfort. Hold his/her hand. Speak gently.

When Death Occurs

People wish to handle the time of death and the events that follow in different ways. The hospice team's first goal is to help prepare you, so you will know what to expect. Your physical and emotional well-being is as important as the dying person's.

- Call the hospice office. A Hospice nurse or other team member will speak with you and may come to your home. Check with them concerning appropriate notices to your doctor, medical examiner or coroner, etc;
- It may be helpful to have a friend or family member come to be with you;
- If you wish, the nurse will call the funeral home for you after the death. The funeral home usually arrives within an hour after the call. You may choose to wait several hours before the funeral home comes if you wish to spend time with your loved one's body or want to wait for other family members or friends to arrive;
- If you have any concerns or fears, call the hospice nurse.

Signs of death include:

- No breathing;
- No heartbeat;
- No response to communication;
- Eyes fixed on a certain spot;
- Eyelids slightly open;
- Jaw relaxed and mouth slightly open.

Practical Issues When A Person Dies

Notifying others that your loved one has died

When a loved one dies, some names will come to you immediately as persons who should be contacted. Close family; good friends; the person's minister, priest, or rabbi; their lawyer and physician. Some calls you will want to make yourself. Other calls have to be made, but you do not need to make them. When a death occurs, both your friends and your loved one's friends, as well as other family members, will want to be of assistance. It makes sense to let others help in passing the word. With friends, for example, or a church or community group, often you can make only one call and ask that person to organize informing others from that circle of acquaintances.

If there are many calls to be made, keep a list of who has been contacted. That way, there is less chance someone important will fall through the cracks.

*“Life is pleasant. Death is peaceful.
It's the transition that's troublesome.*

—Isaac Asimov

Working with the Funeral Home

Normally, within 24 hours of your loved one's death, you should be in contact with the funeral home to set up an appointment with a funeral director. Funeral homes offer a wide range of services at the time of death. These usually include:

- transporting the body from the place of death to the funeral home;
- preparing the body for burial, arranging for a casket and other necessary items for burial, or arranging for cremation;
- working with the family and, if desired, a priest, rabbi, or minister for a funeral or memorial service;
- providing time and space for visitation and a funeral or memorial service;
- assisting in the preparation of an obituary and funeral notice for the local newspapers;
- completing the necessary paperwork for the death certificate, and obtaining certified copies of the death certificate for the family. (Be sure to ask for an adequate number of certified death certificates.) You will need one for each life insurance policy or pension the person had, and several more for processing the person's Last Will and Testament and other financial business. A good rule of thumb is to request at least ten copies;
- transporting the body and family members (if desired) to the funeral or memorial service and/or to the cemetery.

Some funeral homes also offer support groups and bereavement counseling for family members of the person who has died.

Most funeral directors are professionally trained persons who provide their service with compassion and integrity. The role they play in a community is a necessary one, and most do their work sensitively. However, it is important to realize that funeral directors deal with people who are in an especially vulnerable state. When someone you love has just died, if pre-arrangements have not been made, you need to make quick decisions on painful issues. These issues include whether the person will be buried or cremated, what kind of casket to buy, where to buy a burial plot, what kind of service to have. Some of these decisions may involve the outlay of significant amounts of money and may also be emotionally charged, so they become more complicated.

Though most funeral directors will not deliberately use guilt and emotional manipulation to encourage families to purchase high priced goods and services, the following suggestions will minimize the risk of making decisions about which you feel angry or regretful later on.

*“The only courage that matters
is the kind that gets you
from one minute to the next.”*

—Mignon McLaughlin



- Never send one family member alone to see the funeral director. If possible, have two or three family representatives go, one of whom should be more detached from the pain of the loss than a spouse, or sometimes even a child.
- Most funeral homes offer a basic minimum service package. Additional services beyond that are charged individually. Make sure you understand what is included in the basic service, and what will be charged as additional services. Have the funeral director spell out the charges in writing. If you have questions about whether you want or need some of the services offered, go home and think about it, then call back with your answer.
- Money does not equal love. Many people think they must buy an expensive casket or provide a lavish funeral to show their love for the one who has died. This is not true. Buy only those goods and services that seem reasonable to you.

The appointment with the funeral director is usually a part of the business of death that people dread. Arranging for caskets and funeral notices is no one's favorite chore. Try to schedule your visit far enough after your loved one's death that you and significant others have had a night's sleep and have had some time to talk among yourselves about the kinds of arrangements that seem best to you.

If your loved one has joined a memorial society or entered into some other form of prepaid funeral plan, you and other family members will have fewer decisions to make. However, you will also have less control. If you are uncomfortable with the arrangements that have been made, you may have little choice but to accept them and understand that they represent your loved one's wishes.

Planning a funeral or memorial service

After one they love has died, most people find it helpful to participate in some structured ritual of celebration, remembrance, and letting go of the person who has died. Depending on the religious tradition and individual tastes of the deceased person and his or her family, this ritual might range from a Requiem Mass followed by an elaborate wake, to setting a time for family members and friends to get together informally to talk about the one who has died. Such services, both formal and informal, can be a source of comfort and strength, gathering together the community of grief to laugh and cry and remember together.

Below is a list of questions which will help you in planning a funeral or memorial service for a close friend or relative who has died.

- Did your loved one leave any specific instructions about the kind of service that he/she would want? Did those instructions include specific requests for readings, music, a person to preside, or a place where the service was to be held?
- When will it be convenient for the service to take place? Do close family and friends have schedules which have to be worked around in planning the time and place of the service?
- Where will the service take place? If the person belonged to a church, synagogue, or other religious community, when can it schedule a service?
- Who will officiate at the service? Will it be a minister, priest, rabbi, family member, or friend? Do you want an organist, soloist, or other provider of music, and how will those arrangements be made?
- Are there readings, music, pictures, or any other elements which you think would be especially meaningful to you and others as part of the ceremony?
- Do you want to choose someone to deliver a formal eulogy? Do you or other friends or family members wish to offer some personal words of remembrance at the service?
- Do you wish to have visiting hours (a time when people can see the body, say a private good-bye, and speak with the family) before the service? This custom varies from community to community.
- Will there be any kind of reception or other informal gathering of friends and family after the service? Where will it be held?

If you work through a church or other religious community, your contact in that community will undoubtedly have other questions to ask you about the service. However, it is best to think about the questions outlined above before you meet with whoever will be in charge so that you have some idea of what you want.

Other practical issues

Along with the major issues of dealing with the death when it occurs—talking with the funeral director, and planning for a funeral or memorial service—there are other practical tasks large and small which should be attended to in the days and weeks following your loved one's death.

- You will want to contact the person's lawyer regarding the content of his or her will (if one exists) and any other legal business that needs to be attended to.
- You (or whoever has been appointed under the person's will as personal representative of the estate) should contact the person's bank, financial planner, pension administrator, life insurance company, and any others with whom the person had significant financial dealing to inform them of the death. Many of these persons will want certified copies of the death certificate, especially if they are paying out benefits or transferring them to a surviving spouse or joint tenant.
- You should remember to cancel club memberships and magazine subscriptions and have mail delivery stopped or transferred.
- Outstanding bills need to be collected and paid, but this should always be coordinated with other aspects of handling the estate.
- For many families, one of the difficult things to do is to go through your loved one's personal possessions—clothing, papers, mementos, furniture—in order to sort it, sell or give away what the family does not want to keep, and make arrangements for the rest. Like visiting the funeral home, this is a task that is easier if shared among two or more family members.

Taking care of all the business that needs to be sorted out after a death can take weeks or even months, depending on how the person's affairs were organized. It is tiring and emotionally draining work. If you can, share the responsibilities with other family members, do hard tasks with another person, and don't take on too much at one time. It is normal to feel overwhelmed at times with the finishing up of things.

Experiencing Grief and Loss

Anticipated Grief and Loss

Watching someone you love decline in health is a painful process. When death is anticipated, both the patient and their loved ones may experience a normal form of grief. It is called *anticipatory grief*, and is similar to the process of grief following a loss.

Some of the aspects of anticipatory grief that you may notice include:

- Heightened fear, anxiety and depression;
- Increased concern for the well-being of the terminally ill person;
- Imagining the actual event of the death;
- Attempts to adjust to the changes that may occur after the death.

Although anticipatory grief is a painful process, having some warning prior to the death can allow for several things:

- Absorbing the reality of the loss over a period of time;
- Saying good-bye and completing other unfinished business with the dying person;
- Reassigning the family roles of the dying person;
- Gradual withdrawal of emotional energy invested in the dying person.