

Preparing for the Death of a Loved One

Information for Patients & Visitors

This booklet is provided to help you know what to expect when your loved one is dying. It may help you to respond in ways that will help you and your loved one accomplish this transition with understanding and comfort. We know this is a difficult time for you and encourage you to take time to care for yourself and accept the support of friends, family and staff. The team caring for your loved one is also here to support you.



Physical, emotional, spiritual and mental changes are occurring as a person enters the final stages of life.

Physical

The body goes through a number of changes in the final process of shutting down all physical systems. These physical changes are normal and natural, and are ways in which the body prepares itself to stop functioning. The team may be giving your loved one medication to treat pain or shortness of breath. Morphine-like medications are safe to use for this and do not cause death to happen any sooner. They keep your loved one comfortable as they die from their disease.

Emotional

Some people may wish to renew or heal significant relationships. Be prepared to listen and encourage visits from those your loved one wishes to see.

Some people feel they need their family's permission to let go after struggling with an illness. A dying person will sometimes try to hold on, even though it may bring discomfort, in order to be assured that those left behind will be all right. If this may be a concern, reassuring your loved one that they can let go, and not be worried about you, may be a significant gift to them.

Spiritual

Each one of us has inner spiritual strength that helps us to cope with losses, changes and suffering. These inner resources may come from being part of a spiritual or religious community, from nature, relationships or other things that give value to our life. You may be helpful to your loved one by helping them to access their inner strength. This may mean helping to arrange spiritual or religious practices, visits of friends or family, or by listening to your loved one. For some people, being able to talk about important events in their life, the people they have loved, the things they have done, as well what they hope for the people they love, can help spiritual healing.

Your own inner resources can also be helpful to you at this time as you try to cope with seeing one you love at the end of his or her life. Make sure you take time to care for yourself as you go through this journey with your loved one.

Saying Good-Bye

When death is imminent, it is the time to say good-bye in personal ways. It may be helpful to just lay in bed with your loved one, hold a hand, and/or say what you need to say. Tears are a natural part of saying good-bye. They do not need to be hidden or apologized for, as they are expressions of love.

The following signs and symptoms of impending death will help you understand the natural processes that may happen and how to respond appropriately. Each person is unique, hence not all these signs/symptoms occur, nor will they be in the same sequence.

It is hard to predict when a person will die and sometimes it seems that the person is lingering on. Death, like giving birth, is not a completely predictable event.

Fluid & Food Decrease

Food is important in all cultures and preparing food is often a way of showing love for someone. However, at the end of life, there may be a decrease in appetite and thirst, with your loved one wanting little or no food or fluid.

The body does not need much energy at this time and the digestive system cannot process much food or fluids. Do not force him/her into eating or drinking as it will not change what is happening and can cause emotional upset, and/or physical discomfort. When the body does not desire food or fluids an IV is not necessary to keep the person comfortable and can often lead to fluid overload and lung congestion. Lack of fluids in the body is not uncomfortable if the mouth is kept moist.

In the same way, feeding through a tube in the nose or into the stomach does not alter the dying process. There are side effects to the tube feeding including lung infection from food particles entering into the lungs as well as discomfort from the feeds. If you have concerns about your loved one's eating and drinking, please speak with the team involved in their care.

What you can do:

Small chips of ice, frozen juices or Popsicles may be refreshing in the mouth. Be aware of decrease in swallowing ability. Reflexes needed to swallow may be sluggish, so do not give fluids if the person coughs soon after they swallow. The person's body lets him/her know when it no longer desires or cannot tolerate food or liquids. The loss of this desire is a signal that the person is getting ready to die. Use moisturized swabs or a water soluble lubricant to keep the mouth and lips moist and hydrated if your loved one is no longer able to swallow.

Decreased Socialization

Some people like to have people with them all the time. Others may want to be alone or with just one or very few people. This is natural as he/she will be weak and fatigued and not able to socialize much. You may feel that the person is lonely and needs to be more involved in life. However, do not feel that you must always talk; sometimes it is good just to sit together quietly.

What you can do:

Reassure the person that it is okay to rest if they do not wish to talk, or they do not respond to your words.

Sleeping

The person may spend an increasing amount of time sleeping and appear to be uncommunicative, unresponsive, and at times difficult to rouse. This normal change is due in part to changes in the metabolism of the body and brain. Sit with and hold his/her hand, speak softly and naturally. You may wish to spend time when he/she is most alert but just being there whenever you can is fine.

What you can do:

Speak directly and normally, even though there may be no response. **Never** assume that the person cannot hear or feel, as we do not know how well the senses function at this stage of life.

Restlessness

The person may make restless and repetitive motions such as pulling at bed linen or clothing. This often happens partly due to the decrease in circulation to the brain, and metabolic changes. Do not be alarmed, and do not interfere or try to restrain such motions. If you believe your loved one is restless for a reason such as pain, shortness of breath or an uncomfortable position please let the team caring for your loved one know so that they can help.

What you can do:

To have a calming effect, speak in a quiet, natural way, lightly massage the hand or forehead, read to the person or play soothing music.

Confusion

The person may seem confused about time, place and identity of people surrounding him/her, including close familiar people. The team caring for your loved one will try to identify causes of confusion that can be fixed but often this can occur as a natural part of the process of dying.

What you can do:

Identify yourself by name before you speak. Speak softly, clearly and simply when communicating something important for your loved one's comfort such as, "It's time to take your medication so you won't begin to hurt". Do not feel that you must correct their confusion as this can increase the distress of your loved one.

Urine Decrease

The person's urine output normally decreases and may become tea-colored, and concentrated. This is due to the decrease in the intake of fluids as well as decrease circulation through the kidneys. A nurse can determine if there is a need to insert a catheter.

Breathing Pattern Change

The person's regular breathing pattern may change close to death. A particular pattern consists of no breathing for 5 to 30 seconds, followed by a deep breath. Sometimes there is a moaning-like sound on exhaling. This is not distress, but the sound of air passing over relaxed vocal cords. These patterns are very common and indicate a decreased circulation in the part of the brain that controls the breathing.

What you can do:

Elevating the head and/or turning onto the side may change the breathing pattern but this is not necessary as it is a normal part of dying. Hold your loved one's hand. Speak gently and reassuringly.

Congestion

The person may develop gurgling sounds coming from the chest that sound like a percolator. These sounds are from mucous that would normally be cleared if your loved one were more alert and awake. Sometimes these sounds become very loud and they can be very distressing to hear. Watch your loved one closely and note that they are usually unaware of their bodily processes. It is often harder for you to watch than it is for the patient. Trying to suction out the congestion is uncomfortable and most often not successful. Medication that reduces the secretions can be given.

What you can do:

Raise the head of the bed so the secretions stay lower and don't stimulate the gag reflex. Elevating the head and/or turning onto the side may reduce the gurgling sounds. Hold your loved one's hand. Speak gently and reassuringly.

Color Changes

The person's arms and legs may become cold, hot or discolored. The underside of the body may become discolored as circulation decreases. This is a natural change indicating that the circulation is conserving to the core to support the most vital organs. Irregular temperatures can occur as a result of the brain sending unclear messages.

What you can do:

Keep your loved one warm if they appear cold, but do not use an electric blanket. If the person continually removes the covers, then allow them just a light sheet or use a fan to cool them.

At the Time of Death

- breathing ceases
- heartbeat ceases
- the person cannot be aroused
- the eyelids may be partially open with the eyes in a fixed stare
- the mouth may fall open as the jaw relaxes

The body of your loved one is still soft and warm for some time. You can touch their body and hold them if this is what you wish to do. Some people like to stay with the body for some time after death and others do not. Spend as much time with the body of your loved one as you need.

Some people have spiritual or cultural traditions that are done after death. If your loved one dies in a healthcare facility please let the staff know ahead so we can be more helpful to you.

You will need to speak to a funeral director within the first day after your loved one has died, but it does not have to be done immediately. It is always helpful if you have made arrangements with a funeral home prior to the death so that you know who to call, especially at a time when you are feeling stressed.



*This information is provided so the transition
from life to death may be as natural as possible.*

*Please ask your care team
any questions you may have.*



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