

# Preparing for the death of someone for whom you care

Information for family and friends



# Introduction

The purpose of this leaflet is to help you to know what to expect when your loved one is dying, whether this be at home, in hospital, in Hospice, in a residential or nursing home.



At this stage, your loved one may be weak and bedbound, sleeping for much of the day, show very little attention span and sometimes appear a little confused.

They may be unable to swallow tablets and have little or no fluid or food intake.

Managing symptoms is a routine aspect of our care delivery.

The following describes the signs and symptoms of impending death and will help you understand the natural processes that may happen and how you can respond appropriately.

Each person is unique therefore not all these signs/symptoms may 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.

We know this is a difficult time and encourage you to care for yourself and accept the support of friends, family and staff.

Caring for your relative or friend is of the utmost importance to us, and we are here to explain, support and care.

If you have any concerns, please do not hesitate to speak to the doctors and nurses no matter how insignificant you think your questions may be.

## Spiritual

Each one of us has inner spiritual strength that helps us to cope with losses, changes, and suffering in our lives. It may come from being part of a spiritual or religious community, from nature, relationships or other things that give value to our life. Your help may be needed to arrange spiritual or religious practices, visits of friends, family or by listening to your loved one.

You can ask to see a chaplain or other religious leaders who will also help you. 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 as what they hope for, can help. Your own inner resources can also be helpful to you at this time as you try to come to terms with seeing someone you care for dying. Please ensure to take time to care for yourself.

## Physical

The body goes through a number of physical changes. These are normal and natural and are ways in which the body prepares itself to stop functioning.

The staff may give medication to treat symptoms like pain, agitation, and breathlessness.

These medications may include morphine-like drugs which are safe to use for this and do not hasten death. They keep the patient comfortable as they die from their disease.

## Emotional

The person may wish to renew or heal significant relationships. Be prepared to listen and encourage visits. Some people feel they need their family's permission to let go after struggling with an illness.

Sometimes they try to hold on, even though it may bring them discomfort.

Reassuring them that they can let go and not worry about you may be a significant gift.

## Saying Goodbye

Tears are a natural part of saying goodbye.

They do not need to be hidden or apologised for, as they are expressions of love.

## Restlessness

Restlessness and repetitive movements such as pulling at bed linen or clothing may occur. This often happens partly due to the decrease in circulation to the brain and metabolic changes. Do not be alarmed, or try to restrain such movements. If you are concerned that it may be due to pain, shortness of breath or an uncomfortable position please let the team 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 them, or play soothing music.

## Confusion

The dying person may appear confused about time, place and identity of people surrounding them, including close family members. The team will try to identify causes of confusion that can be relieved but often this can occur as a natural part of the process of the dying.

What you can do: Identify yourself by name before you speak. Speak softly, clearly, and simply when communicating something important for comfort such as, 'it's time to take your medication to alleviate your pain'.

## Urine Decrease

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

## Breathing Pattern Change

The regular breathing pattern may change when someone is close to death. A particular pattern consists of breathing irregularly with shallow respirations, or periods 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 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. Holding hands, speaking gently and reassuringly them may be all that is required.

## Congestion

You may notice gurgling sounds coming from the chest that sound like a percolator. These sounds are from mucus that would normally be cleared if they were more alert or awake. Sometimes these sounds become very loud and can be very distressing to hear.

Watch closely and note that they are usually unaware of their bodily processes. It is often hard for you to watch but not distressing for the person. Attempting to relieve the congestion by suction is uncomfortable and often unsuccessful. Medication that reduces the secretions can be given.

What you can do: Raise the head of the bed so the secretions stay lower and do not stimulate the gag reflex. Elevating the head and/or turning onto the side may reduce the gurgling sounds. Holding hands, speaking gently and reassuringly may be all that is required.

## Colour Changes

Arms and legs may become cold, hot, or discoloured. The underside of the body may become discoloured as circulation decreases. This is a natural change indicating that the falling circulation is supporting only the most vital organs. Irregular temperatures can occur as a result of the brain sending unclear messages.

What you can do: Apply warmth if the person feels or appears cold, but do not use an electric blanket. If they continually remove the covers, then allow just a light sheet or use a fan.

## Withdrawing from Society

Some, approaching death, like to have people with them all the time. Others may want to be alone or have just one or very few people for company. This is natural due to weakness and fatigue. You may feel that the person is lonely and needs to be more involved in life.

What you can do: Reassure them that it is acceptable to rest if they do not wish to talk, or they do not respond to your words. Do not feel that you must always talk; sometimes it is good just to sit together quietly.

## Fluid and Food Decrease

At the end of life, there may be a decrease in appetite and thirst, with the person wanting little or no food or fluid. The body does not need much energy at this time and the digestive system cannot easily process foods or fluids.

Do not force your relative or friend to eat or drink 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 a drip 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 tube feeding including lung infection from food particles entering the lungs as well as discomfort from the feeds. If you have concerns about their eating and drinking, please speak with the team involved in their care.

What you can do: Small chips of ice, frozen juices/ice pops may be refreshing in the mouth. Be aware of a 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 sick 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 approaching death. Use moisturised swabs or a water-soluble lubricant to keep the mouth and lips moist.

## Sleeping

Your loved one may spend an increasing amount of time sleeping and appear to be uncommunicative, unresponsive, and at times difficult to arouse.

This is due in part to changes in the metabolism of the body and brain.

What you can do: Sit and hold their hand, speak softly and naturally. You may wish to spend time with them when they are most alert but just being there whenever you can be is fine. Speak directly and normally, even though there may be no response. Never assume that they cannot hear or feel, as we do not know how well the senses function at this stage of life.

# At the time of death

- Breathing ceases
- Heartbeat ceases
- Unroutable
- The eyelids may be partially open with the eyes in a fixed stare
- The mouth may fall open as the jaw relaxes

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

Spiritual and cultural traditions sometimes require specific acts or procedures to be carried after death. Please let the team know of any such traditional rite in advance so that they can be more helpful to you.

You will need to speak to a funeral director after the death, but contact does not have to be 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.

The Hospice Team are constantly striving to improve the standard of care and would welcome your comments or suggestions.



If you would like further information or would like to speak to a member of the team, please do not hesitate to contact us on 647400



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