

Information for Patients and Families When the End is Near

Palliative Care

Compassionate, holistic care at the end of life, when a person is no longer considered curable, is referred to as palliative care.

Your palliative care team may consist of one or more of the following: nurse, social worker, doctor, dietitian, chaplain, pharmacist, and volunteer.

This booklet is intended for patients and families and will help you understand the dying process. Although it is impossible to prepare completely for this event, we believe that coping with death may be made easier if you know what to expect.

The following describes the physical and emotional signs of approaching death. Not all of these will happen to every person, nor will they happen in any particular order. Death comes in its own time, in its own way. Dying is as unique as the person who is experiencing it. Death may be viewed as an end to suffering and the beginning of healing.

Providing accurate, honest information is an important part of care. We hope this information will help you understand the final stages of life and help you deal with the changes that lie ahead.

While reading this booklet, questions or concerns may arise. Please feel free to discuss these with your palliative care team.

For the Caregiver

This is a time when family members feel many emotions: sad, helpless, angry, guilty, peaceful or hopeful. It is a time to hug, touch, and cry or to tell your loved one thing you want to say. Remember that you and your family members need to care for yourselves.

- Make sure that you eat and drink
- Try to spend some time away from the bedside
- Take time for a walk by yourself to think quietly or pray
- Spend time with friends and relatives who support you
- Limit visitors if you feel this is in the best interest of your loved one and your family
- Ask for a visit from your clergy; take part in religious ceremonies that may be of comfort
- Accept help
- Discuss your fears or concerns with your health care team
- Try to avoid sleeping pills and alcohol as they may reduce your ability to cope
- Try to get some rest

Physical Sign of Approaching Death

Sleeping

Weakness and tiredness will increase and more time will be spent in bed.

The person may appear to be in a light sleep much of the time and may be more awake at night. Eventually, the person may sleep all of the time and not respond to voices anymore. It will become difficult to waken the dying person.

Eating and Drinking

When people are preparing to die, they lose their appetite and don't feel thirsty. This may be one of the hardest things for a family to accept. It is all right not to eat or drink.

Food or water will not help to relieve suffering and it will not keep one alive longer. As the body slows down, food and water may even cause discomfort.

Mouth Care

In time, breathing through the mouth becomes more common. The mouth and tongue can become quite dry. It helps to wet the mouth, gums and lips.

Products such as sprays, swabs and gels are available for mouth care.

Pain

Pain does not usually become worse at the end of life. Sometimes there may even be less pain as the person becomes sleepier and moves around less. Medication can be adjusted as often as needed to help relieve pain.

Medication can be given by pills, needle, suppository, patch or continuously by a small pump.

You may hear moaning sounds; moaning does not necessarily mean pain. This may happen when the person is turned or simply breathing out. However, if there is moaning and the person's face shows a grimace or frown, it could mean pain. Extra pain medication may be needed.

Restlessness and Agitation

Reasons why this may happen include:

- Internal body changes
- Medications
- Noise
- Bright lights
- Loud voices

- Fear of being alone
- Emotional distress
- Spiritual distress
- Pain

Often restlessness and agitation are difficult to manage and especially upsetting for families. A nurse or social worker, chaplain or volunteer, may be able to provide much needed support and comfort to you and your family.

Changes in Breathing

There will be short periods of time when the person stops breathing. Long gaps between breaths happen when the person is closer to death. Breathing may become faster, deep and irregular, or may be very shallow. Just before death, the person's breathing will slow down and may seem like gasping.

This is normal. The person is not aware or in distress.

Gurgling in the Throat

Gurgling sounds may occur as air passes over mucus or saliva in the throat when breathing. While this may be disturbing to family members, it is not usually uncomfortable for the person.

Sometimes you may hear a soft moaning sound with each breath. The person is not in pain. This happens when the throat muscles relax. You may hear snoring-like sounds as the jaw drops or the tongue moves back.

Emotional Signs of Approaching Death

The person may experience many emotions throughout the dying process.

- Grieving the loss of future life experiences may cause sadness
- Fear of how death will occur is very common
- Feelings about being a burden and concerns for family members may also occur.
- Spirituality can be a source of comfort; however maintaining faith may be difficult.

The person becomes quieter and less interested in his/her surroundings.

There is a loss of interest in activities such as reading, watching television and being with people. Closer to dying, the person may prefer to have only very close loved ones at the bedside.

“Vision-like” experiences may occur. The person may speak to or see people and places not visible to others. He or she may confuse time and places and may not recognize family and close friends.

Near the Time of Death

The arms and legs may feel cool to the touch and colour changes may occur.

Often, the eyes will be open and not blinking. The mouth may also be open.

The person may become alert even though he or she has not talked in a while, then becomes quiet again. Death usually happens very quietly and peacefully.

At the Time of Death

The signs of death are:

- No breathing
- No response
- No heartbeat
- Eyelids slightly open
- Jaw relaxed
- Urine or stools may pass as the body relaxes

When Your Loved One Dies

Your health care team will give you information about what to do if your loved one dies at home. Remember, this will be an expected death and you do not need to

call 911. You do not need to rush to call the doctor or nurse.

This can be a very special time with your loved one. You may be surprised to find that you feel quite peaceful and calm. You may even feel a sense of relief. Loved ones may feel guilty about this which is a normal reaction.

A Final Thought

Our hope is that this booklet has helped you to understand the dying process. It may not answer all of your questions or deal with every situation.

Your palliative care team is committed to assisting you in this journey.

Notes
