Sunnybrook
HEALTH SCIENCES CENTRE

# Palliative Care Unit K1E

## The Last Hours or Days of Life

This information package is designed to increase your awareness of the changes that occur during the last hours or days of living and how symptoms are managed. Your doctor or nurse has determined that only a little time remains. How long is not certain, but you and your family need to be prepared.

We are aware that things have not been easy for your loved one and your family to this point. Care at the end of life takes into consideration both the needs of your loved one as well as your own. It is a time of changes in the care plan, and it is a time of watchful expectation and sadness.

**Please read all of the information that follows.** In all likelihood, your doctor or nurse has already discussed this with you. If you have any questions, please do not hesitate to contact your nurse, doctor or any member of the palliative care team.

## *The K1E Palliative Care Team*

The interdisciplinary Palliative Care Team is composed of professional health caregivers who are focused on meeting the needs of the patient and their family as the patient nears the end of life. We are here to help you. Let us know how we can best meet your needs. Your nurse is your primary contact with the health care team. The nurse is skilled in assessing patient's needs and relaying information to the team, and can direct you to other members of the team as needed. If you have concerns about symptoms at the end of life, bring theses concerns to your nurse so that they may be addressed promptly.

## *The Physical Changes and Needs*

### 1. Weakness and Sleepiness

You may notice some changes in the person's energy and need for sleep at the end of life. Your loved one may feel increasingly weak, and much more tired. These changes usually happen over a few days, but sometimes this happens very quickly over a few hours.

The person may now be spending all of his or her time in bed. Try to keep the person flat in bed or with their head raised only a little, although this may not be possible if short of breath. The patient may be placed partly on their side, supported with pillows along the whole length of their body. The person's position does not have to be changed frequently at this time.

The person may appear to be in a light sleep all the time, and may be more awake at night. In very few cases, the person will be in a coma. Coma should not be feared. It is just a deep sleep, and does not cause any pain or distress to your loved one. You do not need to be quiet when around your loved one. Speak with normal voices. However, avoid very loud noises, they may startle and disturb the person, and lead to more distress.

Always talk to your loved one as if he or she can hear everything. The person may be too weak to respond or may not be able to speak, but they will still be able to hear and understand what you say. Tell your loved one things you want to say. Hug, touch and cry – all of these things are important to you and your family, as well as to your loved one.

## 2. Eating, and Drinking

This is also a time when the person will eat or drink very little, if at all. At this stage, the person may have no desire for food or water. We recommend that you do not pressure your loved one to drink and eat if they decline the fluids or food that are offered, since this will not help their suffering, and it will not keep them alive longer. In fact, when body systems slow down, food and fluids may not be processed properly and can worsen symptoms such as nausea and shortness of breath. If you try to feed someone who is very sleepy or if their swallowing mechanism is not functioning properly, the food or fluid may go down into the lungs, which can cause breathing difficulty, so be very careful. When food or fluid enters the lungs it may cause obvious symptoms such as coughing and shortness of breath, but occasionally causes no obvious symptoms at the time. Therefore, it may not be safe to offer food and drink during the last hours or days of life. Check with your nurse if in doubt about giving fluids.

If the person asks for water, you may give water with caution. Raise the head of the bed a little or support the person's head, and offer ice chips or small amounts of water using a small spoon. Do not use a straw. If there is coughing or trouble breathing while you are giving the person water or food, stop immediately.

We do not recommend the use of intravenous fluid (administered via a needle in a vein) unless there are special circumstances. The solutions used in the intravenous are composed of salt or sugar and water, and they do not give the person any nutrition. The intravenous fluid does not give the patient comfort and may actually have the opposite effect, increasing or prolonging their suffering by causing edema (fluid build-up) throughout the body, shortness of breath and overproduction of secretions that are difficult to clear.

## 3. Bladder and Bowel Function

If the person has difficulty with urination or is unable to leave the bed to pass urine, a urine catheter (a tube placed into the bladder) may be inserted; it does not cause pain and can be very helpful. Alternatively, incontinent products may be used. If oral laxatives can no longer be swallowed, an enema may be given to promote the passage of stool.

## 4. Mouth and Eye Care

It is important that you help your loved one at this time with mouth and eye care. Often you may find the person is breathing through their mouth and is taking in very little fluids. The lining of the mouth and tongue can become quite dry, causing the person some distress. Frequent mouth care will help this problem. A toothbrush dampened with plain water can be used to refresh the mouth.

A baking soda solution can be used with a sponge tip swabs to clean and freshen the lining of the mouth, the gums and the tongue. We use a solution made with ½ teaspoonful of baking soda mixed in a Dixie cup of water. Your nurse can mix this up for you to use. Sometimes, the person may bite down on the sponge when you first put it in their mouth. This is a normal reaction by the person to protect the mouth. If this happens, continue to hold onto the stick – after a few moments, the person will not bite it anymore. When using a sponge tip swab, excess moisture should be squeezed from the sponge before using in the mouth. You may also apply a soothing lip balm to protect the lips. It helps to do mouth care as frequently as possible, even every hour. Your nurse will provide this care when you are not there.

At this time, some people are unable to keep their eyelids closed during sleep or they blink less often. Artificial tear drops or ointment will be provided for relief of their dry eyes.

## 5. Pain

Pain relief is an important goal of end of life care. We are vigilant in monitoring pain and medication requirements. In some cases, pain does not get worse at the end of life and medication requirements may stay the same or decline. In other cases, pain may escalate requiring an increase in pain medication. Your doctor may need to adjust medications to accommodate these changes.

If the person can not swallow, the doctor will change the way the pain medication is given. The person may receive pain medications by injection every 4 hours plus additional doses for breakthrough pain, using a subcutaneous injection port that uses fewer needles or they may receive a continuous infusion of medication administered by a pump.

Sometimes you may hear the person moaning or appear in distress. This may happen when you move the patient from side to side, or when they breathe out. It can be difficult to determine if expressions are caused by pain. Sometimes moaning may be caused by restlessness or agitation, in which case a sedative medication can be given.

If you see the person's forehead is scrunched up it could mean they are in pain, and pain medication will be given.

## 6. Restlessness and Agitation

Sometimes your loved one can become very restless or agitated. At this time it is very unlikely to be caused by pain. It is more likely to be due to the internal body changes taking place at this time. Sedative medication will comfort your loved one and will be ordered at this time.

## 7. Changes in Breathing Pattern

As weakness increases, you may notice changes in breathing patterns. The most common thing you will see will be short periods of time when the person stops breathing temporarily. The amount of time the person stops breathing may get longer as they come closer to death. Your loved one will not notice these periods and will not be distressed by them.

Other times the person's breathing, particularly near death, becomes more rapid, deeper and regular. This is due to acid imbalance in the body and does not cause the person distress.

Oxygen is unlikely to help the person in either of these situations. The person is not lacking oxygen, and is not aware of what is happening.

Just before death, the person's breathing will slow down, and it may seem like they are gasping. This is quite normal and at this point, the person is not aware or in distress.

## 8. Gurgling in the Throat and Secretions

Very near death (a few hours or a day or two), you may hear the person gurgle or make a snoring-like sound with each breath. During this time the person will be extremely drowsy and may not respond at all. These noises are due to several causes – infrequent swallowing and small amounts of mucus accumulating in the throat, the jaw dropping back, or the tongue moving back due to the relaxation of jaw and throat muscles. Sometimes a soft short moaning sound with each breath out may accompany this. This will never result in suffocation or death from a blocked airway. Again, be reassured that

your loved one is not in pain, but these sounds are due to pooling of secretions and/or relaxation of throat tissues.

Trying different positions as tolerated may help. Doing this will often stop the noises. A medication called glycopyrrolate may be prescribed to dry up the secretions and reduce the gurgling sound. Glycopyrrolate may cause dryness of the mouth. Mouth care is important to relieve dryness caused by glycopyrrolate. Suctioning of secretions from the throat is very rarely needed and may cause a lot of distress.

## 9. Very Near the Time of Death

Occasionally, in the last hours before death, a person may become surprisingly alert or active for a period of time before becoming unresponsive. This sometimes causes family members to feel that the timing of the death was unexpected. Usually, as death approaches, the person becomes quiet or sleeps most of the time and is not able to communicate or consume anything by mouth. As your loved one comes very close to the time of dying, you may notice blotchiness and cooling of the arms and legs, and the skin is cold to touch. The person's eyes will often be open and not blinking. Do not worry whether or not the nurse takes the person's blood pressure and pulse, they are not reliable signs of impending death.

## *Looking After You and Your Family's Needs*

This time can be one of peace and also of distress for you and your family. It is the ending of a life and a relationship that is important to you. You and your family have struggled to help your loved one and to live with your grief throughout the course of the illness. As death approaches, it can be a time of fear, it can be seen as an end to suffering or it can be seen as a time of hope and healing.

**Be sure to look after you and your family's needs:**

- Make sure you eat and drink.
- Allow yourself some time away from the bedside of your loved one.
- Take some time for a contemplative walk or prayer.
- Surround yourself at times with supportive friends and relatives.
- Ask for a visit from your clergy or participate in appropriate religious rituals and ceremonies that may comfort you.
- Accept as much help from the nursing and support staff as can be provided.
- Don't be afraid to discuss your fears with your health care team.
- Avoid taking sedatives, tranquillizers, or too much alcohol as they may reduce your ability to cope.
- Try and get some rest and sufficient sleep. If you are too exhausted, you may not be able to help your loved one or your family during this time.

During this time family members may experience a range of feelings such as peace and relief or terrible sadness and a release of a more open expression of grief. Tears are important. Don't be afraid to cry. Tears are a sign of love, not weakness.

It is often a time when silence has great meaning and when words do not do justice to the moment. Just being physically present to one another is a significant support.

Concerning children, there may be cultural or family norms that guide the degree to which children are present for, informed of, or involved in events at the end of life. Children may be present in the room. If you need help, our staff can help you in determining a course of action or with ways to discuss death with children.

## *Some Closing Comments*

We appreciate all the care and concern that you have shown your loved one while going through this difficult situation and your willingness to rely on the expertise of the K1E Palliative Care Team.

If you have questions or concerns at any time, do not hesitate to speak to your nurse, doctor or any other member of the Palliative Care Team

Finally, if you feel you need help coping with your grief, please ask to speak to our social worker or chaplain.

# At the end of life…

- Try to keep the person flat in bed or with their head raised only a little.
- Speak with normal voices. However, avoid very loud noises, they may startle and disturb the person, and lead to some distress.
- The person will probably eat very little food, if any. If the person coughs or has trouble breathing while drinking water, stop immediately.
- A urinary catheter may be necessary
- Frequent mouth care can relieve dryness and discomfort.
- At the end of life there may be either less pain or more pain. Your doctor may need to adjust medications to accommodate these changes. If the person's forehead is scrunched up it could mean they are in pain. Pain medication will be given.
- Tell your loved one things you want to say. Hug, touch and cry – all of these things are important to you and your family, as well as to your loved one.
- You may hear the person moaning – this is not caused by pain. If the person is restless or agitated, the doctor may prescribe a sedative medication.
- Breathing patterns may change as the person gets weak and just before death. Your loved one will not be aware of this and will not be distressed by it.
- You may hear the person gurgle or make a snoring-like sound. Again, be reassured that your loved one is not in pain. The person is not aware of what is happening to them. Try changing the position of the person to stop or decrease the noises. A medication called glycopyrrolate is available to dry secretions.
- Usually, as death approaches, the person becomes quiet or sleeps most of the time and is not able to communicate or consume anything by mouth.
- Occasionally, in the last hours before death, a person may become surprisingly alert or active for a period of time before becoming unresponsive.
- Take care of yourself.