

The Temmy Latner Centre for Palliative Care

The Last Hours or Days of Life

This information package is designed to help you manage the care of your loved one during the last hours or days of living. 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 me.

The Physical Changes and Needs

1. Weakness and Sleepiness

You may notice some changes 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. If there is not already a hospital-type bed in the home, your doctor or nurse may order one. This kind of bed makes it easier to care for someone at home. Try to keep the person flat in bed or with their head raised only a little. You may place the person partly on their side, supported with pillows along the whole length of their body. Special soft, long body-pillows are available at most department stores, and can be very useful at this stage. You do not have to change the person's position more than every 6-8 hours. Your doctor or nurse will instruct you on how to do this.

To make this time a little easier, your doctor or nurse may suggest using a *urine catheter* (a tube placed into the bladder) or diapers, so that the person does not have to leave the bed to go to the toilet. A urine catheter does not cause pain, and can be very helpful.

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, food or water will not help your loved one's suffering, and it will not keep them alive longer. In fact, when the body's system slows down, food and water may not be processed properly. If you try to feed someone who is very sleepy, it may cause the food or water to go down into the lungs, so be very careful.

If the person asks for water, raise the head of the bed a little, and feed them ice chips or give them small amounts of water using a syringe or a baby cup with a spout. If you hear the person cough or have trouble breathing while you are giving them water, stop immediately.

You may consider the use of an *intravenous* (a needle in a vein) to give the person some fluids. The solutions used in the intravenous are usually just salt or sugar and water, and they do not give the person any nutrition. The intravenous does not give the patient comfort and may actually have the opposite effect, increasing or prolonging their suffering. We usually do not recommend the use of an intravenous unless there are special medications that can only be given that way.

3. Mouth and Eye Care

It is important that you help your loved one at this time with mouth care. Often you may find the person is breathing through their mouth at this time 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.

Make up a solution of 4 cups of water (1 litre), ½ teaspoon of salt and 1 teaspoon of baking soda. Make a new batch of solution fresh each day. Use this solution and the sponge tip swabs to clean and freshen the lining of the mouth, the gums and the tongue. Sometimes, the person may bite down on the sponge when you first put it in their mouth. This is a normal reaction to protect the mouth. If this happens, continue to hold onto the stick – after a few moments, the person will

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not bite it anymore. As well, use something to protect the lips. Mouth care should be done at least every hour. Your nurse will show you how to do this.

For relief of dry eyes, buy some artificial tears at the drug store and use them in the person's eyes about 4 times a day. Your nurse will teach you how to do this too.

4. Pain

Pain does not usually get worse at the end of life. Usually, as the person becomes more sleepy, moves around less and the body changes, there may actually be less pain. Your doctor may need to adjust medications to accommodate these changes.

If the person can't swallow, the doctor will change the way the pain medication is given. You may be asked to give pain medication orally, by placing it against the lining of the mouth or under the tongue where it can be absorbed. Or, the person may receive pain medications by injection every 4 hours, using a special set-up that uses fewer needles. Your doctor or nurse will teach you about this too.

Sometimes you may hear the person moaning. This may happen when you move the patient from side to side, or when they breathe out. This moaning is not caused by pain. If you see the person's forehead scrunched up it could mean they are in pain, and you should give the extra breakthrough or rescue dose of pain medication as instructed by your doctor.

5. Restlessness and Agitation

Sometimes your loved one can become very restless or agitated. This is because of the internal body changes taking place, or sometimes from a medication. Your doctor may prescribe a medication that can be absorbed from under the tongue or at the side of the mouth. This medication is a mild sedative that will quickly calm and soothe an agitated or restless person. You may need to administer this medication every half-hour or every hour initially, and it may take several tablets until the restlessness stops. Your doctor or nurse will teach you how to do this. This medication will not harm your loved one.

6. Changes in Breathing Pattern

As the person gets weak, you may notice changes in their 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 become 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 will not 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.

7. 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. During this the person will be extremely drowsy and may not respond at all. These noises are the result of several things – small amounts of mucus 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 relaxation of throat tissues.

The best thing to do is to put the person flat in bed on their side. Make sure the person is well supported by pillows all along the back of the body. Doing this will often stop the noises. The doctor may recommend that you go to the drug store and buy a medicine called "Transderm V". This is a small patch that is placed behind the ear and will dry up the secretions. Sometimes, the doctor will use an injected medicine to do the same thing. Oxygen will not help with this problem. Suction machines are very rarely needed and in inexperienced hands, can cause a lot of distress.

8. Very Near the Time of Death

As your loved one comes very close to the time of dying, you may notice blotchiness and cooling of the arms and legs. 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. Occasionally, someone who is unresponsive may suddenly become more alert as death approaches. Do not be afraid. This is not a time of distress.

Looking After You and Your Family's Needs

This time can be one of peace and 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.
- Don't spend all your time at 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 home care program as can be provided. If you have insurance with extended health benefits, you may want to ask your doctor whether you qualify for extra nursing help.
- Don't be afraid to discuss your fears with your health care team.
- Do not take sedatives, tranquillizers, or too much alcohol as they may reduce your ability to cope.
- Try and get some rest, if not some sleep. If you are too exhausted, you may not be able to help your loved one or your family during this time.

This time can be one when there are two sets of feelings: 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.

Please allow children to be present in the room. Help model for them and teach them how a family cares for one of its own. If a child is close to your loved one, they need to be there if they are going to be able to manage their own grief. Help them understand what is going on. Remember children at various ages think of death differently. Do not use phrases such as "God is taking grandma" or phrases that may indicate that death is like sleeping. If you need help, there are resources we can identify that can help you to help children be involved and understand this whole process.

When Your Loved One Dies

- **Do not panic. Do not call 911.**

There is no need to contact any authority immediately, even the physician.

Let your grief be expressed. Often though, you will feel quite peaceful and calm especially if you have had a chance to deal with the grief around the impending loss before death.

Spend some time with your loved one before calling the doctor.

When you are ready, call the doctor. If the death has occurred in the middle of the night, call the doctor first thing in the morning (after 6:30 A.M.) and a doctor will come as soon as possible. In any case, it may take us some time to respond. This should not worry you.

The doctor will fill out a special certificate and then you can call the funeral home.

Some Closing Comments

We appreciate all the care and concern that you have shown your loved one in managing this difficult situation. We could not manage to provide home care without your help, concern and sacrifice.

If you have questions or concerns at any time, do not hesitate to page and speak to the doctor or nurse.

Finally, if you feel you need some help coping with your grief, ask your doctor or nurse for a referral to one of our counseling programs.

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.
- ✚ Frequent mouth care can relieve dryness and discomfort.
- ✚ As the person becomes more sleepy, moves around less and as the body changes, there may actually be less pain. Your doctor may need to adjust medications to accommodate these changes.
- ✚ 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's forehead is scrunched up it could mean they are in pain, and you should give the extra breakthrough or rescue dose of pain medication as instructed by your doctor.
- ✚ Your loved one may become very restless or agitated. Your doctor may prescribe a medication that can be absorbed from under the tongue or at the side of the mouth.
- ✚ 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 putting the person flat in bed on their side to stop the noises.
- ✚ Occasionally, someone who is unresponsive may suddenly become more alert as death approaches. Do not be afraid. This is not a time of distress.
- ✚ When your loved one dies, do not panic. Do not call 911.