



Government of **Western Australia**
Department of **Health**
End-of-Life Care Program

Understanding the dying process

An information booklet for families



This booklet has been compiled to help answer some difficult questions that you may have about the dying process. It is important to remember that just as each person is unique so too will be their death.

It is almost impossible to tell you the exact time or manner in which a person will die. However, regardless of the illness, there are several similar physical symptoms and emotional changes likely to occur as death approaches.

Increasing tiredness

You will find that over time the person will become increasingly tired and weak. Although it is difficult to prevent this from occurring, spacing out everyday activities and ensuring adequate rest will help. It is important to explain this to other family members and visitors. For most terminally ill people this tiredness gradually increases until they finally become unconscious.

Managing anxiety and confusion

Shortly before death some people become restless, agitated and confused, however, they are usually unable to tell us why. This is known as terminal restlessness and it often occurs within the last few days of life and affects nearly half of all people who are dying. There may be a variety of causes for this and sometimes sedative drugs are needed. A calm, quiet and stress-reduced environment, with reassurance from those who are close to the person, can often help to relieve this symptom.

Communication

Extreme tiredness can mean that the person finds it hard to sustain a conversation as they once could. You may find that after resting there are periods when communication becomes easier. If you are concerned that the person has worries or anxieties, rest assured, just being with them will be supportive and comforting. If and when the person becomes unconscious they may not be able to respond to you, however, they will still be aware of your presence and voices around them. Studies indicate that hearing is the last of the senses to be lost. We therefore encourage you to continue to talk to the person even if they appear to be unconscious.

You may also wish to hold or gently massage the person's hands or feet as a way of maintaining physical contact. Playing soft music that the person enjoys can also be soothing.

Managing pain

Many people (but not all) with a terminal illness may experience pain. Pain can be due to a variety of reasons such as pressure on an internal organ, damage to nerves or lack of blood supply. There are a number of medications available which can be prescribed, depending on the nature of the pain. Not all people's pain will respond in the same way to a particular treatment. The required dosage of pain medication varies widely from person to person and it is sometimes necessary to make adjustments to these medications. Pain can often be relieved with simple techniques such as repositioning pillows or bed clothes and gentle massage (if tolerated).

Loss of appetite

Most people lose their appetite in the last few weeks of life. This is a very natural and normal part of the dying process because the metabolism is slowing down and the body requires less nutrition. At this time your instincts may be to try and feed the person in order to keep up their strength.

The giving of food is often symbolic of loving and nurturing and to deprive someone of this may feel like neglect. However, as the person becomes increasingly weak and drowsy, swallowing and digesting food and fluids often becomes harder and can place strain upon the body. While the person may have a reduced oral intake, it is important to maintain good oral care. Regular moistening of the mouth and lips will add to the person's comfort. The health care staff will be happy to show you how to do this if you would like to assist.

Becoming unconscious

When or if this happens, repositioning while the person is unconscious will help prevent soreness and stiffness from lying in the one position for too long. The person may also be provided with a special mattress to increase comfort and relieve pressure. Mouth and eye care are also important at this time. Sometimes an indwelling catheter is inserted to relieve the feeling of a full bladder, but for most people their urine output is significantly decreased and often completely ceases.

As the person is unable to cough, secretions may build up at the back of the throat causing a rattling or gurgling noise as they breathe. This noise can sound distressing to us but may not be a cause of discomfort to the person. Repositioning them on their side can loosen these secretions and there are medications available that may help to dry them out. We rarely use suction as it can be uncomfortable and distressing for the person and the irritation can cause a further build up of secretions.

Before death you may notice a change in the person's breathing pattern. There may be periods of rapid breathing followed by short periods of no breathing. This is known as Cheyne-Stokes respirations and is very common at the end of life.

The unconscious person may still feel pain as they did when they were awake. For this reason pain medication will continue to be administered but perhaps by another method such as the subcutaneous route (through a butterfly clip in the stomach, arm or leg). If you are concerned that the person looks uncomfortable in any way, please inform the health care staff and they will complete a pain assessment.

The dying process

Most carers/family members and close friends want to know exactly how long the person will live. Some people will become unconscious a few days before dying, however, others may die quite suddenly or even remain awake to some extent right up until they die. Each person is an individual so we can never be certain how long the dying process will take.

Once death has occurred

When death has occurred the person stops breathing and their heart stops beating. They will not respond to any stimulation and their mouth may fall slightly open. Their eyes may also be open but the pupils will be large and fixed on one spot. They may also have lost control of their bladder and bowel.

A doctor will usually visit and confirm that death has occurred. You may wish to contact a close friend or relative to be with you for support. Take some time to say your goodbyes. Other close friends and relatives may also wish to say goodbye. If desired, your spiritual advisor or support person can be with you at this time.

A funeral director will need to be contacted at this stage. They can guide family members through the funeral arrangements if these have not been organised already. As the death was expected, it is not usually necessary to contact the police or ambulance services at this time.

Care for yourself

Caring for someone who is dying can be a tiring and stressful time. It may bring up unresolved feelings or upsetting emotions including grief or distress. If this is the case for you, it may help to talk through your feelings. The health care staff or your general practitioner may be able to support you at this difficult time or they may be able to refer you to an appropriate service.

This document can be made available
in alternative formats.

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