

understanding THE DYING PROCESS



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.

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 organ, damage to the 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. Whilst 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 nursing staff will be happy to show you how to do this if you would like to assist.

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.

Becoming Unconscious

When or if this happens, frequent 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 from the lungs 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 the person on their side will loosen these secretions and there are medications available to help 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.




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 may need to be changed to 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 nursing staff and they will complete a pain assessment. Prior to 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 Dying Process

Most carers/family members and close friends want to know exactly how long the person will live. Some people will become unconscious for a few days prior to dying, however, others may die quite suddenly. Each person is individual so we can never be certain how long the dying process will take. If the person is in hospital or in an aged care facility, whenever we can, we will move the person to a single room to provide privacy and quiet. This enables close family and friends to remain with the person if they wish. For this reason, hospitals and aged care facilities often do not have strict visiting times.

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.



Contact your nurse or doctor to help you confirm that death has occurred. If you are alone with the person, you may wish to contact a close friend or relative to be with you for support. Take your time to say your goodbyes. The person's body may remain at home, in the aged care facility or in the hospital ward for several hours. Other close friends and relatives may also wish to say goodbye. If desired, your minister or support person can be with you at this time.

If you are at home, contact the funeral director when you are ready and they will guide you through the funeral arrangements. As the death was expected you are not required to contact the Police or Ambulance services. If you do decide to contact these services you need to be aware that they are required to follow their normal protocol.

Care for yourself

Caring for a dying person can be a tiring and stressful time. If you would like to talk with someone please speak to a nurse or doctor involved in the person's care. The hospital and palliative care service offers the support of Social Workers who can spend time with you to help you deal with family and relationship issues. There are also Pastoral Care workers who are able to guide you through any spiritual or religious needs you may have. Trained palliative care volunteers are also available to sit with the dying person. Your general practitioner will be able to support you at this difficult time.

We hope that this guide has answered some of your concerns. If you have any other questions please ask your doctor or nurse for more information.



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