

Palliative Care and Disability

Fact Sheet Series

#7

Information for Disability Accommodation Services staff working in Group Homes

The Process of Dying

Caring for someone during the last few weeks and days of life can be stressful and demanding. Many different feelings may come up. This leaflet helps you to understand and respond to some of the signs you may notice. Carers are often concerned that death will be a painful experience for the person. However, the time before death is generally peaceful. There is a gentle winding down that may take several days. The body starts to 'let go' of life. If restlessness does occur, it can be treated.

Not all the signs discussed in this fact sheet will occur with every person. Sometimes these signs appear a few hours before death, sometimes a few days. These physical signs are part of the normal, natural process of the person's body gradually slowing down. Apart from the signs described here, you may notice other changes that worry you. The palliative care team is there to assist you at all times by providing information and support. Please ask for help at any time. The team expects to have more contact with you in the last stages of the person's life.

You can bring great benefit to the person you are caring for just by sitting with them, holding their hand and speaking in a calm and reassuring voice. Even if the person does not respond, they can probably hear you. 'Being with' can be more important than 'doing for'.

Changes you may notice and what you can do to help

Social Withdrawal - is normal for the dying person. They become less concerned about their surroundings. Separation begins first from the world then from people.

Disorientation - The resident may become confused about time, place and the identity of people around him/her. He/she may see people who are not there. This can be distressing to family or health care professionals. There is no need to 'correct' the resident if he or she is not distressed.

Decreased Senses - Clarity of hearing and vision may decrease. Soft lights in the room may prevent visual misinterpretations. Never assume that the patient cannot hear you, as hearing is the last of the five senses to be lost.

Appetite and Thirst - The person's appetite and thirst may decrease, and they might not want to eat or drink. This is natural and is not painful for the person. Sips of water, chips of ice to suck, or a moist mouth swab will help. Trying to feed someone who is unable to swallow may make them upset.

Sleep and Alertness - Changes happening in the person's body mean that they may spend a lot of time asleep or may be drowsy. It is best to talk to the person when they seem most alert, and allow them to sleep when they want to. There is no need to shake the person or to speak loudly. It is best to speak softly and naturally.



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Temperature - The body's temperature may change. At one time the person's hands, feet and legs may be cool to the touch, and at others they may be hot and clammy. Sometimes parts of the person's body become blotchy and darker in colour. This is due to the blood circulation slowing down and is a normal part of the dying process. If the person indicates that they feel cold use light bedding to keep them warm. Too many bed clothes or an electric blanket may make them hot and restless. Provide good ventilation. A fan to circulate the air and cool damp towels can help if the person seems hot.

Incontinence - The amount of urine decreases due to the reduced amount of fluid the person is drinking. The urine may become stronger and darker. Many carers are concerned that the person will lose control of their bladder and bowels. This does not happen to all people, but if it does there are pads and special absorbent sheets to improve comfort and hygiene. A rubber sheet protects the mattress. A member of the palliative care team can tell you about what is needed.

Secretions - As coughing and swallowing reflexes slow down, saliva and mucus may collect in the back of the person's throat, causing a gurgling, bubbling or other noise. This noise can be a concern to carers, but does not usually cause distress to the person. To help improve the situation you can elevate the person's head and support them with pillows so that their head is turned to one side. Medications can also be given to slow down the production of saliva and mucus to improve comfort.

Breathing - Regular breathing patterns may change. Sometimes the breathing may be rapid, and at other times there may be long gaps between breaths. Breathing may be shallow or noisy. This, too, is due to a slowing down in blood circulation and a build-up in the body's waste products. It is not painful or distressing for the person.

Restlessness - Due to the decrease in circulation of blood to the brain and to other changes happening in the body, the person may become restless or agitated. To have a calming effect, speak in a quiet natural way, lightly massage the person's hand or forehead, or softly play familiar music. Let a palliative care team member know if the person becomes restless or agitated. Medications can be given to reduce the problem.

How will you know that death has occurred?

- Breathing ceases
- No heartbeat or pulse
- The person cannot be roused
- Eyelids may be half open
- Pupils are fixed

What should you do?

Follow your guidelines, but there is no rush. It is important that you do everything in your own time. The person's body can stay at home for several hours if you would like friends and relatives to come and say their goodbyes. It is a good idea to turn off or remove sources of heat such as room heaters, electric blankets and hot water bottles. It is helpful to let the police know that a death is expected and tell them not to wear uniforms when they come to the home.

Adapted from the Palliative Care Victoria Brochure – The process of dying



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