

How will you know that death has occurred?

You will know that death has occurred when:

- The person stops breathing;
- There is no heartbeat or pulse;
- The person cannot be roused;
- The person's eyelids may be half open, and
- The person's pupils are fixed and do not respond to light.

What should you do?

If the person dies at home, you do not have to contact anyone immediately, unless you want to. It is important that you take the time to do the things that you need to do in your own time, there is no need to hurry. If you need someone to be with you at this time, it may be best to telephone a relative or friend.

If the person dies during the night, it is quite acceptable to wait until morning before you notify the doctor or nurse, however this is your choice, and you may also wish to call them immediately.

Following death, a person's body can stay at home for several hours, particularly if you would like friends and relatives to drop by to say their goodbyes. During this period, it is a good idea to turn off or remove sources of heat, including room heaters, electric blankets and hot water bottles. It is also important to ensure that the person is lying straight, as over time, their limbs will stiffen. Feel free to replace their dentures if they had been removed previously.

If there is visible perspiration or body fluids that worry you, it is OK to swipe them away with a damp cloth. Although some people may wish to do so, it is not necessary to bathe the person completely. If it would make you feel more comfortable, the palliative care nurse can help you to do this. Shaving a person after death requires special techniques and is best not done at home.

In your own time, and when you feel ready to do so, contact the funeral director. Your funeral director will collect the person's body and step you through the funeral process, helping you to make any arrangements that need to be made at that time. If you require additional information about planning a funeral, PCQ's brochure *'Planning A Funeral Ahead Of Need'* is available upon request.

This fact sheet was produced by Palliative Care Queensland, the peak organisation for Palliative Care in Queensland, representing the interests and aspirations of all who share the ideal of quality care at the end of life for all. To order additional copies of this fact sheet, or to become a member of Palliative Care Queensland, please contact:

Palliative Care Queensland Inc.

Postal Address:

PO Box 437, Virginia, Qld 4014

Street Address:

117 Copperfield Street, Geebung, Qld 4034

Freecall: 1800 660 055

Office: (07) 3633 0096

Fax: (07) 3633 0086

Email: enquiries@palliativecareqld.org.au

Website: www.palliativecareqld.org.au

For more information about palliative care services in your local area, please contact:

Palliative Care Information Service (PCIS)

Phone: 1800 772 273

(Monday to Friday 9am – 5pm)

Website: www.pcis.org.au

Email: info@pcis.org.au

PCIS is a free telephone information and support service available to all Queenslanders affected by terminal illnesses, including patients, family members, carers and health professionals. PCIS provides emotional support, counselling and general information about Palliative Care and end-of-life services in Queensland. Support is provided by trained professionals who have access to a large database of up-to-date information.

Disclaimer

The information contained in this brochure is for general guidance only and is not clinical advice. All efforts have been taken to ensure that the information provided is accurate and up to date at the time of printing. The information provided is intended to help inform patients and their family. Your healthcare decisions are best made in consultation with your doctor

Acknowledgement

Palliative Care Queensland acknowledges Palliative Care Victoria (PCV) and Palliative Care Australia (PCA) for the contribution from their information brochures. PCQ also acknowledges the role of PCQ Education Committee in modifying and reviewing this document.



**Palliative
Care
Queensland**

About the Process of Dying

Information for Carers

Despite the fact that all human beings die, many people in our community remain quite fearful of the process of dying. This may be because they have no experience of seeing someone die, or because they have no experience of caring for a terminally ill person during the final days or hours of life. This brochure aims to alleviate this fear by providing patients and carers with information about the process of dying.

Caring for a person during the last few weeks and days of life can be a very stressful and demanding time. It is normal that a variety of feelings and emotions may surface. This information may help you to understand, anticipate and respond to some of the physical signs that you may notice during this time.

Dying is not always painful

Many people believe that death is a painful experience, however in the majority of cases, good palliative care enables death to occur in the absence of physical pain or discomfort. The period before death is generally quite peaceful, and often follows a gentle 'winding down' that may occur over several days as the body starts to 'let go' of life. During this period, if restlessness or other symptoms occur, they can be treated very successfully.

This brochure discusses many of the signs and symptoms associated with the process of dying, though not all the signs discussed in this leaflet will occur with every person, nor will they occur in any particular sequence. Sometimes these signs appear in the hours prior to death but they can also occur in the days leading up to death. It is important to remember that these physical signs are part of the normal, natural process of dying.

Apart from the signs described here, you may also notice other physical changes that may concern you. In all cases, rest assured that your health care team is there to assist you, provide information and support your needs. Feel free to ask questions and ask for help at any time. Your team will expect increased contact with you towards the end.

Importantly, you yourself can bring enormous benefit to the person you are caring for simply by sitting with them, perhaps by holding their hand and by speaking in a calm and reassuring manner. Despite the fact that your loved one may not respond during this time, it is more than likely that they can still hear what you are saying. Don't underestimate the value of these simple things. 'Being with' can be more important than 'doing for'.

Changes you may notice and what you can do to help

Appetite and Thirst

The dying person's appetite and thirst usually decrease, and mostly they have little or no desire to eat or drink. This is often a concern to many carers, however it is a natural process that is not painful or distressing for the person. Although sips of water, chips of ice to suck, or a moist mouth swab can help a dry mouth, attempting to feed someone who is unable to swallow may cause distress.

Sleep and Alertness

Changes within the person's body mean that they may spend a lot of time asleep, may be drowsy or difficult to wake. It may be best to talk to the person when they seem most alert, but also to allow them to sleep when they wish. There is no need to shake the person or to speak loudly. It is best to speak naturally.

Temperature

During the process of dying, the body's temperature may fluctuate. Sometimes the hands, feet and legs may be cool to the touch, and at other times they may feel hot and clammy. Sometimes parts of the person's body may be blotchy and darker in colour. This is due to the circulation of the blood 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 bedclothes or an electric blanket may make them hot and restless. Always provide good ventilation, perhaps by using a fan to circulate the air. Cool damp towels can help if the person appears hot.

Incontinence

The amount of urine produced decreases as the person gets closer to death, usually because the amount of fluid the person is drinking has reduced. The urine may become stronger and darker in colour. This is normal.

Many carers are also concerned that the person will lose control of their bladder and bowels, however this does not happen to all people. If this does occur, pads and special absorbent sheets are available to enhance comfort and hygiene. Special sheets are also available to help protect the mattress. Speak to a member of your healthcare team if you have concerns about incontinence, they are best placed to advise you about what is needed at that time.

Secretions

As dying approaches, coughing and swallowing reflexes slow down, and as a result, saliva and mucus may collect in the back of the person's throat. This can sometimes cause a gurgling, bubbling noise. Although this noise often alarms carers, it does not usually distress the dying person. This situation can often be improved by elevating the person's head and supporting them with pillows, so that their head is turned to one side. Medications can be given at that point to slow down the production of saliva and mucus and thus improve comfort.

Breathing

During the process of dying, the person's regular breathing patterns may change. Sometimes their breathing may be rapid, and at other times it may appear that there are long gaps between breaths. Their breathing may also be shallow or noisy. Please remember that this is a normal part of the dying process, and that it is not painful or distressing for the dying person.

Restlessness

Due to the changes that affect the brain during the process of dying, the person may become restless or agitated. If this happens, try to speak in a quiet natural way. Lightly massaging the person's hand or forehead, or playing soft familiar music can help. Always advise a member of your healthcare team if the person becomes restless or agitated, as there is medication available that may help to alleviate the problem.