

PATIENT INFORMATION - FINAL DAYS OF LIFE

What happens in the final days of life?

Knowing that you or a loved one is close to dying can be very difficult for everyone involved. People often ask questions about how someone will die, especially relatives and friends. They often worry that they will not be able to cope or know what to do when the person they are caring for dies. It is very difficult to give exact details of how someone will die. Each person is different and will die in their own unique way. But we can give you some general information about what may happen and what you can do to support your loved one through their process of dying.

Physical changes

The body begins its natural process of slowing down all its functions. How long this takes varies from person to person - it may take hours or days. It can be emotionally very difficult to watch someone go through these physical changes but they are part of a natural dying process and don't mean that the person is uncomfortable or in distress.

When death is very near, the dying person may experience:

- **Sleepiness and difficulty waking (semi-conscious)**

People who are dying often sleep a lot and may not respond when you try to wake them. But this doesn't mean they can't hear you so it is important not to stop talking to them or comforting them. You can sit close to them and hold their hand. It is important not to say anything that you wouldn't want them to hear. It's also a good idea to tell them when you enter or leave the room.

- **Difficulty swallowing or not wanting to eat or drink at all**

Having difficulty swallowing may be one of the first signs that somebody's condition is beginning to deteriorate. Your Hospice nurse or GP will check to ensure that this is not because of anything that could be treated, such as oral thrush. It is common for people to lose interest in eating and drinking and very often all they may tolerate is a few teaspoons of food such as yoghurt or ice cream. There will come a time when the dying person will not want to eat or drink anything. It is important not to try and force them to eat or drink as this will make them uncomfortable and may cause coughing/spluttering or gagging. If they are still awake you can give them crushed ice to suck or sips of fluid to keep their mouth moist. You can put lip balm on their lips to help stop them getting dry and sore. If they really can't take anything into their mouth, you can moisten their lips, the inside of their mouth and their tongue with swabs dipped into water or another drink that they enjoy. Ask your Hospice nurse for some mouth swabs.

- **Loss of bladder and bowel control**

The dying person may lose control of their bladder and bowel. This happens because the muscles in these areas relax and don't work as they did. This can be very distressing to see and you will worry that they may feel embarrassed or lose their dignity. A urinary catheter may be an option for some people. As people become very close to death and are not eating or drinking, the amount of urine and stools they produce gets less and less. Occasionally

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when somebody passes away, their bladder or bowel may empty. The Hospice nurse can give you some draw sheets, nappies or pads.

• **Restlessness**

You may notice increased restlessness, pulling at bedclothes and trying to get out of bed when they are too weak to stand. There are many reasons why restlessness occurs, such as a full bladder or bowel, confusion and disorientation, pain, spiritual distress and emotions such as anger, guilt or fear. Let your Hospice nurse or GP know if restlessness is a problem and they can check to see if this is because of pain or other physical symptoms which can be relieved. Having loved ones near to comfort and support will bring reassurance.

• **Confusion**

Your loved one may seem muddled and confused or say things that make no sense. They may appear to not know who you are or may act in a way that is out of character, which could be hurtful and upsetting to you. You can help by saying who you are, talking calmly and clearly and holding their hand or touching them gently if they find this comforting. Being in familiar surroundings and maintaining their usual spiritual and cultural practices such as karakia (prayer) and waiata (song) may help.

• **Changes in breathing pattern**

When someone is dying their breathing often changes and often there may be short or long gaps between breaths. If their breathing is laboured or breathlessness has been a problem, a small dose of Morphine may ease this, even if they are not in pain.

• **Noisy breathing**

You may hear gurgling or rattling sounds as the dying person takes each breath. This is due to a build-up of saliva that they are unable to swallow or cough up. Sometimes secretions may pool in their mouth and leak out. Changing their position in bed or raising their head and turning it to the side may help to drain the secretions. You may find it distressing to hear this but it is not usually distressing for the person dying. Medication may also be prescribed but may not prevent this altogether. Some people wonder about using a suction machine. Suctioning can cause distress and discomfort and may increase the production of secretions, so this is not usually an option.

• **Cold feet, hands, arms and legs**

The dying person's face, hands, arms, feet and legs often become very cool to touch. Their skin may also become pale and look blotchy or mottled. This happens because there is less blood circulation to these parts of the body. Keep them warm with blankets but don't use an electric blanket as this may become uncomfortable. Thick socks can help to keep their feet warm. Don't overheat the room as this can make it stuffy. Just keep it at a comfortable temperature.

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• Complete loss of consciousness

At the end of life the dying person slips into unconsciousness. This is usually right towards the end, maybe only a few hours or days before death. You won't be able to wake them at all. Their breathing will stay irregular for some time and will at some point stop.

How will you know when your loved one has died?

- Their breathing has stopped
- They do not respond to talking or touch
- Their eyes may be fixed on a certain spot or their pupils may appear dilated (large); their eyelids may be open
- Their mouth may stay open
- Their bladder and/or bowel may be empty
- They will not have a pulse or heartbeat

What do you do when your loved one has died?

- You don't have to do anything straight away - take your time to collect your thoughts.
- You may want to:
 - Have family or friends with you for support and to say goodbye to your loved one
 - Contact the Hospice nurse to let her know and ask any questions you may have
 - Reposition your loved one onto their back with their head on a flat pillow
 - Contact your cultural and/or spiritual support person at this time
- When you are ready you can contact the funeral home you have chosen and they will guide you with what you need to do. They will contact the GP to confirm the death.
- If you wish to undertake funeral arrangements yourself, seek guidance from the *Before Burial or Cremation* information brochure from the Department of Internal Affairs.