



Facing the unknown

What to expect when someone important to you is dying

Te Kahu Pairuri mai i Takarunga ki Te Hana

harbour
hospice

The logo for Harbour Hospice features a stylized white bird or wing icon above the word "hospice" in a bold, sans-serif font. The word "harbour" is written in a smaller, lowercase font above "hospice".

**Kia hora te marino,
kia whakapapa pounamu te moana,
kia tere te kārohirohi i mua i tōu huarahi, ā,
ko tōu hoa haere ko te rangimārie**

May the calm be widespread,
may the ocean glisten like greenstone,
may the shimmer of light
dance across your pathway
and may peace itself be your travelling companion

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At Harbour Hospice we realise this particular period of time can be difficult and unfamiliar for you, your family and whānau.

At a time when your family and whānau are naturally concerned about the possibility of approaching death, we believe that open, honest and straightforward communication both establishes trust in our Hospice and best serves your family's needs.

Experience has shown us that fear of the unknown is often greater than fear of the known. That is why we offer this information – to help you become aware of, anticipate and prepare for symptoms and situations that you may have to deal with.

If you have any questions about the information in this booklet, please discuss it with your hospice nurse, your district nurse or your GP – they are your best resources to clarify any concerns.

What you can expect from the care and support offered to a person nearing the end of their life

- The person's situation should be recognised and reviewed regularly by the care team.
- We aim to sensitively communicate with the person and those who are close to them and involved in their care.
- We respect the person's wishes, and those who are important to them should be involved in the decisions about how they are treated and cared for.
- We endeavour to meet the needs of the person's family, whānau and those who are important to them – as far as this is possible.
- An individual plan of care will be agreed with the person and family, whānau and carers.
- The person's specific needs (if they have any) will be put into their individual care plan and communicated to the care team who will attempt to meet these needs as far as they are able.

Signs of approaching death

There are certain changes that signify a person is likely to be close to death. It is normal for some of these changes to come and go over a period of days.

All the signs described are how the body is preparing itself for the final stages of life.

However, not all these symptoms appear at the same time and some may never appear.

If you are caring for a person at home a hospice nurse may be contacted by telephone 24 hours a day, seven days per week for support. Specific contact details will be provided by the care team to the family, whānau and carers.

A reduced desire to eat

It is common for people with advanced disease to have a reduced desire to eat. If you have concerns please discuss this with your nurse. They will be able to give you helpful ideas for meals and/or food supplements.

If a person stops eating or drinking because of their reduced appetite this may be hard to accept, but it is a normal part of the dying process. It may also be hard for them to swallow tablets.

If they stop drinking, their mouth may look dry but this does not always mean that they are dehydrated as the body adapts to the reduced intake.

how you can help

- Offer ice chips, sips of fluid through a straw, or use a feeding cup which makes it easier to give small amounts of fluids.
- Mouth swabs soaked in water help relieve the feeling of dryness and keep the mouth and lips moist. The patient may want to suck on these. Your hospice nurse will supply them – please ask.
- Lip balms or Vaseline can also be useful.

An increase in sleepiness

The person is more likely to spend more time sleeping and will often be drowsy even when they are awake.

They may also drift in and out of consciousness. Some people can become completely unconscious for a period of time before they die.

how to help

- Usually people are happy to have normal, everyday happenings carry on around them while they doze.
- Plan time with family and whānau for those periods when they are more alert and open to visitors.
- If your loved one is in the Hospice Inpatient Unit (IPU) the nurses can assist if visiting needs to be restricted.
- You may want to ask the person what they would like you to do when they can no longer speak.
- You might want to carry on letting them know you are there in other ways such as holding their hand, reading to them or playing their favourite music.

Deteriorating hearing and sight

how to help

- Keeping a light on may be reassuring if their sight is affected.
- Never assume that they cannot hear. Hearing is always the last of the five senses to be lost and is present even when someone is unconscious.

Increased confusion about time and place

how to help

- You may like to display a clock and calendar with large figures to help the person keep track of the time and day.
- Try to keep familiar objects of special significance close by. If your loved one is in the Hospice Inpatient Unit you may want to bring items into Hospice to help with this.

Not recognising people close to them

If the dying person does not recognise you during this time, this may be distressing for you. However, it is not a sign that they feel any differently about you. It is more likely that they are unable to distinguish between what is real and what is not, especially if they are a bit sleepy and drifting in and out of consciousness.

how to help

- Speak clearly and audibly to the person.
- Talk to them, reminding them who you are and be prepared to do so repeatedly.
- Try not to correct them if they say something wrong as this may be distressing for them and for you.



Restlessness, delirium and/or agitation

This is called terminal restlessness. Signs may be twitching, plucking at the air or bedclothes, attempting to get out of bed even when unable to stand alone, moaning and calling out.

A person's terminal restlessness may be due to treatable causes such as constipation, difficulty passing urine, pain, anxiety or it may also be caused by the irreversible effects of advanced disease.

Some people may have experiences that hold spiritual or cultural value for them.

They may also start to hallucinate and see people or things that are not actually there.

how to help

- Talk with your Hospice Nurse or GP who will investigate and take steps to relieve their restlessness.
- Having someone stay with your loved one may be sufficient to relieve their restlessness.
- Create an atmosphere of calm with such things as music, aromatherapy and soft lighting.

Cool extremities

The person's arms and legs may become cool to touch and you may notice their skin changing colour. This is due to the changes in their circulation.

how to help

- You do not need to warm them up but if their skin feels cold, keep warm blankets on.
- Do not use an electric blanket as the constant heat can damage the skin and make it more prone to pressure sores.
- Keep the room warm, but ventilated.

Flushed and hot appearance

Sometimes the skin may appear very flushed and hot – even though the person doesn't feel hot. This is usually not an infection but a change in oxygen levels in the brain.

how to help

- Applying cool, moist cloths to the forehead can relieve the hot flushing of the skin.

Shallow breathing

As the person's body becomes less active in the final stages of life less oxygen is needed and breathing may become shallow. There could be small periods of no breathing, followed by a large gasping breath. Doctors and nurses refer to these as periods of 'apnoea'. These symptoms are very common and indicative of a decrease in circulation.

how to help

- Repositioning often helps. Elevating the head of the bed, either with pillows or a back rest, may relieve the irregular breathing patterns.
- Although apnoea can be frightening for you, it does not usually cause distress to the person. Apnoea is different from the shortness of breath that your loved one may have experienced previously.

Noisy breathing

If the person is too weak to cough and swallow, or is semi-conscious, he or she may develop rattling and noisy breathing. You may have heard people refer to this as the 'death rattle'.

The cause of this is the build-up of secretions that are normally found in the throat and lungs. This is usually more distressing for you than it is for them. Small amounts of secretions can produce this symptom – they are not drowning.

how to help

- Repositioning them on their side with the head of the bed slightly lower than the foot will help and may be all that is needed.
- If the secretions become excessive the hospice nurse can consult the doctor about medication that may help dry the secretions.
- Suctioning is rarely used as this can be more distressing for the person than the noisy breathing.

Loss of bladder and bowel control

This happens because the muscles in these areas relax and don't work as well as they did. This may be distressing to see and you may worry that the person feels embarrassed.

how to help

- Keep the person clean and comfortable.
- Offer reassurance and comfort.
- Also ask the nurse for equipment that may be able to help, such as a catheter, incontinence products, or a Kylie (mattress protector) to cover the bedding.

Reduced bowel and urine output

The person may have fewer bowel motions as they eat less. You may also notice that the amount of urine passed decreases and that the colour is darker.

Pain

how to help

- Look out for cues which may tell you if the person is in pain, such as wincing, flinching, clenching their teeth, stiffening their body or scrunching up their forehead.
- Let the nurse or doctor know as they will be able to check the person and give more medication to help if this is needed.

The person's eyes are closed

It is important to know that in these final stages the person may close their eyes often. At some point they may not open them again. Their eyes may often be half open which can be distressing to see.

How you will you know that death has occurred

The process is unique to every single person and it is difficult to predict exactly when a person will die or to know exactly what changes the person you are caring for will experience when they are dying.

In the last few minutes of their life, the person's face muscles may relax and they can become very pale. Their jaw may drop and their eyes may become less clear. The person's breathing will become much slower and quieter before it eventually stops. Often the person's body will completely relax.

This can be a profound moment, even if the death has been expected for days. You may suddenly feel overwhelmed with sadness; you may want to be alone, or you may want to phone family, whānau and friends.

By this time you may be exhausted from the caring and the waiting, and both the relief and finality of the moment of death can take you by surprise.



When your loved one has died

You do not need to notify the funeral director immediately.

Many families have found that keeping their loved one in the familiar atmosphere of home for a few hours after death enables them to say 'goodbye' in an unhurried and special way.

Your doctor will need to be notified so that they can complete the necessary legal requirements.

Your Hospice care team is available to assist you with any special requirements or concerns you may have at this time.

Bereavement support

Grief at the loss of a loved one is an experience unique to each individual.

Harbour Hospice has a team of professionals available to support you including nursing and medical staff, counsellors, social workers, spiritual and cultural advisors.

We can support families and whānau if desired with regular phone contact, home visits and grief counselling by appointment.

We also offer a range of group programmes for family, whānau and carers at each of our centres. This means support is available in your local community.

If transport is an issue for you, we can arrange for a volunteer driver to help.

Visit harbourhospice.org.nz for more information on programmes available near you

Hibiscus Coast

2a John Dee Crescent, Red Beach
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