Care at the end of life:
supportive information for whānau

Capital & Coast
District Health Board
ŪPOKO KI TE URU HAUORA

PATIENT INFORMATION

Palliative Care

When a person is dying, their needs change, as does the care they require from hospital staff. Some of this care may seem different to what has been offered previously, however the doctors, nurses and other health professionals will talk to you about what is happening and explain what is going on as much as they are able.

This information is designed to help whānau understand changes that occur in treatment, decision making, communication and the needs of the person who is dying. It gives practical tips about caring for the person who is dying, as well as ways to ensure that you are caring for yourself.

Please contact us if you are uncertain about anything.

Information and communication

This section will cover some information around who we will contact, and what we will do to keep you updated about what's happening.

Caring for your whānau member is important to us – please don't hesitate to speak with the team about any concerns or worries you might have, no matter how insignificant you think they might be, or how busy the staff may seem.

We are aware that some of the words that we use can cause confusion. If you don't understand what we are saying, ask for more information or for us to explain it differently. It is a good idea to write down questions you might have so you remember for the next time you are speaking to someone.

There may be things about your whānau member that are important for us to know - have you ever talked about what they would want at the end of life? Did they have specific wishes about how they would like to be cared for in this situation? Who would they like to have around? What things bring them comfort?

Who should we contact?

We welcome whānau participation in, and decision making about our care. It is helpful for us to have a nominated person who we can use as the main point of contact and who will relay messages to the wider whānau. This person is also who we will contact if we need to provide updates or discuss care with anyone. This person will be known as the Next of Kin (NOK) or First Contact, and are often nominated by the person in hospital at the time they are first admitted.

If you are the NOK, check with the staff that the contact details we have are correct. You can also let us know when you would like to be called – e.g. when the doctors visit or if you would like to be phoned if things change in the night. Someone will be available to talk things through if there are any questions – just ask the nurse.

Decision making - Next of Kin (NOK)

There is no legal definition of NOK. It usually translates to the nearest relative of the person in hospital or somebody that they have nominated to be contacted by the health care staff looking after them.

When a person is named or chosen to be the NOK they DO NOT assume any kind of legal responsibility or authority. However we will involve NOK in decision making if this is something the patient wants.

In hospital, there is one contact person listed as a NOK in the system and a second contact person if NOK cannot be reached. Only these people will be able to have calls put through to the person whilst in hospital, so it is important that everyone knows who they are. This doesn't mean that visitors are restricted, however the hospital will only discuss potentially sensitive information with the nominated NOK.

Decision making - Enduring Power of Attorney (EPOA)

When a person is unable to communicate their wishes for themselves, decisions can only be made by another person if that person has already been appointed to act as the EPOA.

EPOA is defined as a written authority given by a person, whilst they are competent (thinking clearly and able to make rationalised decisions), to another person, to act for the welfare of the person only once they are mentally incompetent. This document is drawn up by a lawyer and a medical certificate from a doctor is required before a person with EPOA can act on the person's behalf.

If you have been appointed as EPOA, let us know - we will ask for a copy of the documents. If there is no EPOA in place and the person is no longer competent to make decisions for themselves, members of the healthcare team will be able to discuss what might need to happen now.

A changing focus of our care

The doctors and nurses caring for your whānau member will discuss how care may be delivered now that they are identified as dying and in the last hours to days of life. This is likely to mean that there is a change of focus from procedures such as monitoring pulse, blood pressure and giving multiple medications to more of a focus on comfort.

This does not mean that there is less care being given but that care is given in a different way. Medications are reviewed with a focus on those things that will be helpful for pain or distress. These may also need to be given in a different way.

If you wish to help in the hands-on care you are very welcome to do so, please talk to the nursing staff about how they can support you with this. You can also request cultural or spiritual support during this time - ask the nursing staff to make a referral for you to Whānau Care Service, Pacific Health Services or Chaplaincy Service.

Our aim is for comfort, dignity and to ensure that the needs of your whānau member are being met.

Taha Tinana - physical well being

The next section talks about some possible changes that you might expect to see as a person enters the final few hours to days of life and are dying. At the end of this section there are some tips around ways that whānau can help.

Changes in awareness and confusion

Occasionally, people can become restless, pulling at bedclothes or trying to get out of bed. They can also seem muddled or disorientated. There can be many reasons or causes as to why this might happen - as the body slows so does the body's ability to function in its usual way. The medical and nursing team can help explain this if you want to understand more.

Changes in breathing patterns

When a person is dying, it is common for their breathing pattern to change. There may be long pauses between breaths, or breathing may become more shallow or rapid. You may also be able to hear a noisy rattle, as secretions (such as saliva) collect in the person's throat. This can sound distressing to those around but from our experience it is not thought to be distressing for the dying person.

Managing bladder and bowel control

It may become difficult for the person to control their bladder or bowels as they become weaker and become less aware. The nurses caring for them will do all they can to maintain their dignity and keep them clean and comfortable.

Changing colour and temperature

You may notice that the person becomes cool to the touch, particularly on their arms and legs. The colour of the skin may change, becoming mottled or pale. This is a normal part of dying, as the circulation begins to close down.

What can whānau do to help?

- If distressed or agitated, keeping a calm environment can help. Avoid bright lights.
- Gentle touch can be reassuring, such as holding the persons hand or stroking their arm.
- Listening to familiar music can be calming.
- If the person does not settle, talk to the nurse as there may be a physical cause such as pain that may need to be assessed and managed.
- Changing position can be helpful to aid with breathing and noisy secretions. Some people prefer to have their own pillows from home and you would be welcome to bring these in.
- If you have any concerns please speak with one of the staff - medications may be needed to help maintain comfort.

Kai - foods and fluids

Not eating or drinking

Near the end of life, it is natural for a person to no longer be interested in or be unable to eat or drink. This is often one of the hardest things to accept because food is associated with nurturing and love. Tastes may change and cravings come and go. Eventually there will come a time when food and fluid are neither wanted nor needed. As death nears and the body slows down it is no longer able to digest food and fluids in the same way. This is a natural process and not distressing for the person.

What can whānau do to help?

- Let the person decide what and when they want to eat or drink.
- Respect the person’s wishes by trying not to force the person to eat or drink. Eating when not hungry can cause vomiting, choking and discomfort.
- Offer a selection of small, easy to eat foods and fluids.
- To prevent choking, offer food and fluid only when the person is awake and alert enough to eat and swallow.
- Provide frequent mouth and lip cares with moistened swabs and lip balm to provide comfort.
- Discover other ways to show love and support such as giving a massage, reading aloud and telling stories.

Taha Whānau – the well being of the whānau

Here you will find some suggestions about looking after yourself, as well as the person who is dying.

Caring for someone who is in the final weeks and days of life can be physically and emotionally demanding. It is important that you take care of yourself. Trying to balance someone else’s care with your own needs for rest and food can be difficult.

You may not feel like eating regular meals, but it is important that you try to eat when you can and take regular breaks.

During this time you may have questions about visiting and staying in hospital. We do our best to accommodate whānau on the ward and allow flexibility with visiting. Please talk to the nurse if you have any specific questions regarding accommodation and visiting.

Taking care of ourselves

When someone is dying it is tempting to put your entire life on hold to spend time with them. It is important that you continue to take care of yourself so that you can remain emotionally available for the person who is dying and the people around you.

Taking care of yourself means:

- eating properly, drink water and fluids and don't skip meals
- talking to your whānau, friends or other supportive people in your life about how you are feeling
- making sure your own emotional, spiritual and cultural needs are maintained. These are the things that help you to cope with stress and difficult situations
- getting plenty of rest; the nursing staff will contact you or your whānau spokesperson if they need you. Take a break - a walk in the fresh air can give you some much needed space
- talking to hospital staff about how you are feeling if you think that would be helpful. They can arrange for chaplains, social workers or kai awhina to spend time with you if you need it.

Taha Hinengaro - emotional well being

There are some common changes to people's emotional well-being when they are dying. Some of the changes you might see and ways to help manage these if they do occur.

When someone is dying it is natural for them and the people around them to experience a wide variety of emotions. These may include denial, fear, anger, relief, joy, and peace as well as many other emotions. It can be a confusing time and some may become distressed. However it is important to remember that there is no right way for anyone to feel throughout this time.

For many people fear is a common emotion. The doctors, nurses and other health professionals will answer your questions as best and as honestly as they can so that you can continue to support and care for your whānau member without being frightened of what is to come.

People who are dying may want to talk about their lives, past events, regrets or people that they have known. They may want to see people that they have not seen for a long time, right past wrongs, make amends with people they have fallen out with, or they may wish to be alone. It is important to remember that the way they are feeling is unique to them and that provided it is not causing them further distress or harm it is ok to do things their way.

Some people can appear distressed and it may be difficult to work out if the cause of this is emotional or if it is a symptom of their illness. If you are unsure about the distress your whānau member is experiencing, talk to the nursing staff.

What can whānau do?

- Provide compassion - this means allowing the person to be just the way they are, even if they are totally different to the person that we remember.
- Be sensitive - acknowledge and support the person with whatever they are feeling.
- Reconcile - if you or the person that is dying have something to reconcile and it is the right time, this may be a helpful part of your time together.
- Provide comfort - read to them, sing to them, talk to them, pray with them, let whānau and friends say goodbye, listen to their stories, or simply be with them as much as you and your life allows you to.

Taha Wairua – spiritual well being

When a person approaches death - spirituality, faith, beliefs and religion can have stronger importance then they have previously. Knowing what is important to the person now, what brings them comfort, and who or what might offer a sense of peace is of great value.

Some people can have very strong dreams or visions. For some this is a source of comfort, whereas for others this may be distressing. Medication can be given if this is causing distress.

What can whānau do to help?

- Bring in belongings that hold personal meaning, favourite music, clothing, photographs or religious items or spiritual symbols.
- Let the staff know if there are specific religious needs as staff can contact a member of the hospital chaplaincy.
- Read quietly to the person if they would like that.
- Talk to the person about memories and stories of significant people, or times in their life even if they may seem unresponsive.
- Consider asking for spiritual or cultural support. The nursing staff can arrange a referral to the Chaplaincy Service, Pacific Health Care Services or Whānau Care Services for you.

Bereavement and after death care information

Information is available about what happens after someone has died in the hospital, and the process that will be followed by hospital staff.

For some whānau members this information can be helpful to have even before the person has died. If you wish to know more about this please let a member of staff know.

Our cultural and spiritual support services are experienced in supporting whānau through death in the hospital.

Tissue donation

Donated tissues can help others to live and to have an improved quality of life. When someone dies it is often possible to donate eyes, heart valves and skin after their death, regardless of where the person has died.

- Transplantation of cornea (the clear tissue at the front of the eye) can restore sight. Transplantation of sclera (the white part of the eye) can repair eyes that have been damaged by injury or disease.
- Heart valves can be transplanted to save the lives of children born with malformed hearts or other people with diseased or damaged valves.
- Skin can help to save the lives of people with severe burns, as well as reducing pain and scarring.

People of all ages can be considered for transplantation. Age and medical history will determine which tissues can be donated. People with cancer can donate their eyes, even though they cannot donate heart valves or skin.

- Tissue is removed with the same care and respect as any other medical procedure and can take place a number of hours after death.
- Donation does not prevent families from having their family member at home.
- Funeral arrangements, including having an open casket are not affected by donation.

If you would like to talk to a health professional about the option of tissue donation, please contact the donor coordinator, Organ Donation New Zealand, 24 hour number: (09) 630 0935. The coordinator will be able to answer any questions you have and will provide you with further information.

Sources of support and resources

The following is a selection of support groups and resources available in the Wellington area. Your GP, Community or Social support organisation, Chaplain, faith community/ church, Whānau Care Services, or Pacific Health Service may be helpful places to start.

Youthline (Wellington office)

A team of volunteers available 24/7 to talk through anything by phone, text or email.
Phone: (04) 801 6924 - available 24/7
Website: www.youthline.co.nz
Cost: Free

Skylight

Skylight is a person-centred counselling service for people of all ages who have experienced loss or grief. Includes pre-schoolers, children, teenagers and adults.
Contact: Freephone 0800 299 100
Hours: Monday to Friday 9.00am-5.00pm
Website: www.skylight.org.nz
Cost: There is a cost but it is reduced for community service card holders. Low income families may be eligible to assistance from WINZ.

Widowed, separated or divorced (WSD) NZ

Support groups in Wellington and the Hutt Valley to help those who have lost a partner through separation, divorce or death.
Website: www.wsd.org.nz

Samaritans

The NZ Samaritans is a confidential listening AND support telephone service operating 24 hours a day for people who may be feeling depressed, lonely or even contemplating suicide.
Phone: 0800 726 666 - available 24/7
Website: www.samaritans.org.nz
Cost: Free

Talking works

A web based resource of registered counsellors.
Website: www.talkingworks.co.nz
Cost: variable

Association of NZ counsellors

A web based resource of registered counsellors
Website: www.nzac.org.nz
Cost: variable

Work & Income New Zealand

May provide financial assistance to cope with any financial changes as a result of your loss.
Phone: 0800 559 009
Website: www.workrkandincome.govt.nz

Whānau Care Services at CCDHB

Working with you to achieve the best health outcomes for māori patients and their whānau.
Level 2, Cultural Centre, Wellington Regional Hospital
Phone: (04) 385 5999 ext 80948 or
DDI: 04 806 0948
Email: wcs@ccdhb.org.nz
Hours: 8.00am-6.00pm Monday to Friday

Pacific Health Services at CCDHB

Working with you to achieve the best health outcomes for Pacific Island patients and their families.
Level 2, Cultural Centre, Wellington Regional Hospital
Phone: (04) 806 2320
Hours: 8.30am-5.00pm Monday to Friday

Chaplaincy

Providing spiritual and pastoral care to all patients, their families and staff within the hospital setting.
Phone: extn 82124 or extn 82126
Chapel: Level 2, Cultural Centre, Wellington Regional Hospital

Kenepuru Community Hospital & Ratonga-Rua-O-Porirua

Ecumenical Chaplain
Phone: 04 385599 Ext 7542

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