

Living Every Moment



hospice
taranaki



Information Guide

For Patients, Families/Whanau, Carers

24/7 SUPPORT 06 753 7830

Values

Fairness – Tika

Compassion – Aroha

Honesty – Pono

Respect – Whakaute

Choice – Puwharu

Trust – Whakawhirinaki

Dignity – Whakarangatira

He aha te mea nui?

He tangata, He tangata, He tangata

What is the most important thing?

It is people, it is people, it is people



Welcome

The team at Hospice Taranaki appreciate how difficult a life-threatening illness can be; not just for the patient, but also for the people who care for them. Illnesses such as cancer can turn our whole world upside down – there are so many questions we need to ask and so many things we need to do.

With over 20 years' experience of providing care to people in this very situation our team has vast amounts of knowledge and experience ... and they are here to support you and answer any questions you might have.

We know that a life-threatening illness will impact on many areas of your life, so over the years we have developed services to meet a wide range of needs, the team at Hospice Taranaki will be there to support you every step of the way.

This booklet is designed to introduce you to our services and answer questions you may have about how Hospice Taranaki can help you. However if at any time you want more information or support please do not hesitate to contact us.

Contents

Referral.....5

Introduction.....6

Palliative Care.....10

What to expect as a patient16

Symptom Management.....18

Support24

Practical information27

On-going Support.....31

Complaints Process33

House Rules for Te Rangimarie34

Records37



Referral

Patients are referred to our service because it is felt that his/her illness (whether cancer or non-cancer) is no longer medically curable and that the quality of life could be enhanced by a palliative approach.

Hospice palliative care is patient and family/whanau-centred and recognises the physical, emotional, psychological and spiritual elements that are faced by patients and their family/whanau.

Hospice palliative care Philosophy

- Hospice palliative care affirms life.
- Hospice palliative care recognises dying as a normal process and neither hastens nor postpones death.
- Hospice palliative care exists to help patients and families attain a degree of separation for death which is satisfactory to them.
- Hospice palliative care recognises grief as normal response to loss. Support for the family is offered up to and following the bereavement period.
- Access to hospice palliative care is available in a culturally appropriate manner and is based on need.
- Hospice palliative care is available free of charge.

Introduction

Our Mission

“To provide the best quality hospice palliative care services to patients and families throughout the region free of charge.”

Overview

Though the word “Hospice” may suggest something physical like a building it is actually a philosophy of care.

While the in-patient unit, Te Rangimarie, in New Plymouth is at the heart of our service, Hospice Taranaki provides an extensive service to patients in the community throughout Taranaki. This means we provide care in people’s own homes either through our own nursing team or the District Nursing teams.

Hospice Taranaki is an independent organisation, we receive funding from the Taranaki District Health Board but also rely heavily on donations, grants and community fundraising activities to cover the shortfall we need each year to ensure our services are provided free. We work in collaboration with our colleagues in Taranaki’s two hospitals as well as with the District Nurses, GPs and the residential care facilities of the province.

What services does Hospice Taranaki offer?

Our service is comprehensive and inter-disciplinary*, designed to meet the needs of people with life threatening illness, their carers and families/whanau. The team at Hospice Taranaki work as an inter-disciplinary* team who ensure that the patient and their family/whanau remain at the centre of all care provided. The services provided are free of charge.

The team can be made up of professionals including:

- 24/7 telephone support
- Medical staff and medical specialists
- Nursing staff
- Counsellors
- Social workers
- Occupational therapists
- Physiotherapists
- Complementary therapists
- Dieticians
- Chaplains
- Kaiawhina (Cultural Support)
- General Practitioner
- Ambulance services

Referrals for other specialised care can be made to Taranaki Base Hospital or Hawera Hospital health professionals and patients can also access the St John Ambulance supporters scheme which provides ambulance trips in an emergency.

The comprehensive care includes in-patient care at Te Rangimarie in New Plymouth and community care throughout the province. Hospice Taranaki also has access to two beds in the Hawera Hospital for in-patient care.

*inter-disciplinary: medical, nursing, counselling, physio, occupational health, spiritual working together collaboratively with a focus on the patient and family/whanau.

We work in partnership with other health professionals, community agencies and hospital services. We try to ensure that the general practitioner remains the patient's key medical professional, with other health professionals involved according to needs at the time.

Communication with other professionals involved in the patient's care is maintained by effective care co-ordination and communication between all the professionals involved. Often, the palliative care team take on the role of care co-ordination and will involve other services if needed.

Your Rights

Hospice Taranaki upholds the provisions of the Code of Health and Disability Services Consumers' Rights. The Code details 10 rights relating to how you should expect to be treated when receiving services for Hospice Taranaki.

- You should always be treated with respect.
- You should expect fair treatment.
- You should expect services which support you to live a dignified, independent life.
- You have a right to be treated with care and skill.
- You have the right to be listened to, understood and receive information in whatever way you need.
- You have the right to have your condition explained and be told what your choices are.
- It's up to you to decide. You can say no or change your mind at any time.
- You have the right to have someone with you to give you support in most circumstances.

All these rights apply if you are asked to be involved in any research undertaken by the Hospice.

You have a right and it is OK to complain. Your complaints help us improve services.

*If you would like a copy of the Health and Disability Commissioner's Code of Rights ask your Community Nurse or give us a call on 06 7537830.

Accessing Patient Clinical Records Information

All patients have the legal right to view and have copies of their clinical records as this is covered by the Health Information Privacy Code. If a patient registered with Hospice Taranaki would like to view or have copies of their records, the patient can make contact with the Privacy Officer and request this. The Privacy Officer can assist the patient to understand the records which are kept.

A family member/patients representative may request information about the patient and this can be provided with the written permission of the patient. If the patient is unable to give permission, the Privacy Officer at Hospice Taranaki can use his/her discretion in granting this request and may involve seeking permission from the Executor of the estate if the patient has died. The family member/patients representative will need to confirm their identity for access to be considered. They may also need to contact Taranaki District Health Board for permission for any clinical records which may be kept at Medical Records.

To contact the Privacy Officer, phone Hospice Taranaki 06 753 7830.

Complaints process

Hospice Taranaki staff and volunteers are constantly striving to provide the best quality care for patients, family/whanau and carers, however should you have any concerns we welcome your feedback. Full details of our complaints process can be found in Section 10 of this booklet.

Feedback of all kinds is welcome and can provide a valuable opportunity for improvements to be made to our service.

Palliative Care

Where is palliative care provided?

Palliative care may be provided in many different locations. The principle of “best palliative care in the bed you are in” is recognised as being important. This may mean that the patients may be seen in the community – in their own home, in a family member’s or carer’s home, in a residential facility (rest home), in a hospice bed or in hospital.

Sometimes when patient needs are complex or care needs are greater than what can be provided in a particular setting eg: home, an alternative place of care may be considered such as a residential care facility.

Occasionally a high level of care (known as Hospital Level of Care) is required for a longer period of time. In these cases the patient may be admitted to a residential care facility with hospital level care available. The Hospice Taranaki Social Worker helps in these instances.



In the Home

Palliative care is provided in the community by the Hospice Taranaki Community nursing team and/or District Nursing teams throughout Taranaki. We work very closely together to ensure that palliative care is provided in the best and most effective manner.

Family/whanau members and carers generally provide most of the care to patients in the community and the palliative care team provides support to help them to do this. Sometimes this support may be education and training on how to care for someone at home or how to care for someone who is confined to bed. The staff work with each patient/family/whanau to identify how best to provide this support at any given time. Education and support is a key role of the palliative care team in all areas of care.

The specialist palliative care team at Hospice Taranaki provide advice and support on almost a daily basis to outlying areas where district nurses are the main palliative care nurses.



There are number of services we provide to help care for patients and family/whanau in the community:

Equipment loan – a variety of equipment is available and includes beds, lazyboy chairs, commodes, walking aides, bathroom furniture, pressure relieving mattresses and cushions, mobility scooters and other items. Generally this equipment is available for use at home only as residential care facilities have access to their own supply of equipment within their facility. Hospice Taranaki will deliver this equipment to the patient's home as needed.

Home-based support services – including home help, personal hygiene (ie: shower/bath) assistance, meal preparation, overnight carers, companion (respite) sitters to stay with the patient to allow their carer to have time out. In discussion with the patient a referral is made to the TDHB for an assessment.

Respite care – is available for short periods of time to allow your carer/s time to rest or have a break. Respite care may be offered in the inpatient unit Te Rangimarie or within a residential care facility. Respite care is generally for a week and is arranged in consultation with the patient and family/whanau.



In Residential Care

As Hospice Taranaki's 7-bed inpatient unit is not a long-stay facility, patients may sometimes be discharged to a residential care facility for ongoing care.

If a patient is not able to be cared for in their own home and need residential care, an assessment will be arranged to be undertaken to ascertain the care needs. The hospice team remain involved and visit the residential facility and support their staff with on-going care.

A Social Worker will be available to assist patients and family/whanau with advice on facilities and funding of residential care.



Inpatient Unit

Te Rangimarie Hospice
5 David Street, Westtown, New Plymouth
Phone 753 7830

Although many people wish to stay at home throughout their illness, there are times when, for a variety of reasons patients may find it impossible to stay at home. When these situations arise patients can be admitted to Te Rangimarie for in-patient care or respite care.

Patients may be admitted for symptom management, respite care or end of life care. Te Rangimarie is not a long-stay facility and admissions are usually for no more than a week although individual circumstances are the key determinant of length of stay.

Te Rangimarie has seven private rooms in an environment which as home-like as possible with 24 hour clinical care.

We want patients to feel 'at home' when staying at Te Rangimarie and we want family/whanau and friends to feel comfortable visiting and/or staying here as well. House rules are displayed on page 34 and in all patient rooms and family areas at Te Rangimarie to guide expectations. These rules are in place to ensure the safety, security, privacy and comfort of patients and their visiting family/whanau and friends, are maintained during your stay. A copy of these rules are included in Section 10, please take a few moments to read them.

Family/whanau and support persons are welcome to visit Te Rangimarie Hospice without restriction to any set hours.



Outpatient Clinics

The patient's general practitioner (GP) is the lead medical carer in the community but sometimes an appointment will be arranged for review by a palliative care doctor at Te Rangimarie. This appointment may be for a variety of reasons including a review of medications, or an assessment of symptoms. The hospice doctor will inform the GP of any changes or suggestions which may occur as a result of the review.

Wellness clinics

When the patient is well enough, appointments may be made to attend a nurse-led clinic at Te Rangimarie for assessment, intervention and evaluation. The aim of these clinics is to provide care and support while allowing the patients to retain their independence for as long as possible.

The patient will have the opportunity to familiarise themselves with the in-patient unit and when appropriate meet other members of the hospice team.

Taranaki Base or Hawera Hospitals

Often the hospice service receives referrals from the medical team in hospital. Hospital team members visit the patient and family/whanau in the ward to introduce the hospice service and also liaise with the medical and nursing staff at the hospital. The hospice staff can offer advice and support to the patient and family/whanau and the hospital team.

What to Expect

Assessment and Care Planning

When initially referred to Hospice Taranaki a staff member will be in contact to arrange a time to complete an Initial Assessment. Information from this initial assessment is used to develop a Care Plan to meet the patient's needs. The patient will be involved in developing and reviewing the care plan as needs change.

The staff caring for the patient will use this care plan to identify specific needs at any given time. It allows members of the wider team to understand care needs as well.

Family Meetings

Family meetings are held as a way of supporting families as well as patients. They may be suggested as a way for the patients/family/whanau or significant others to meet to discuss care planning, discharge planning, goals of care, information sharing and/or as an opportunity to express concerns or discuss issues.

The family meeting is facilitated by a member of the hospice interdisciplinary team and can occur in Te Rangimarie, hospital or at home with the GP present.

At the conclusion of the meeting a plan will be developed to address any issues discussed and it provides an opportunity for all those involved to have the same information and goals in mind.

GP Shared Care

The patient's GP remains the lead medical professional whilst patients are in the community. Hospice Taranaki staff liaise regularly with GP's to discuss changes in care needs or the review of medications.

Other Shared Care Arrangements

In special cases Hospice Taranaki has shared care arrangements in place with Taranaki Base Hospital Paediatric service; Alcohol and Drug service; Maori health providers; Mental Health Unit and Older Persons Health Service.

Hospice Taranaki has linkages with the Cancer Society; Child Cancer Foundation; Canteen, Art Therapy Service and Season's Grief programme.



Symptom Management

Hospice Taranaki staff are trained to manage symptoms that may be causing concern. There can be a variety of symptoms that may occur and everyone is different. If as a patient you notice a change to your normal body patterns or change in your condition it is really important that you tell your visiting nurse or GP. You can also call Te Rangimarie Hospice (06 753 7830) any time of the day or night if it is urgent.

Medication safety at home - Managing symptoms is an important part of good palliative care. Staff will explain and provide educational information in regard to your medication. You will be provided with a medication chart which will help guide you in the use of medication for specific symptoms.

It is important you inform your visiting nurse of any new medication that is prescribed or which medication is discontinued. This will ensure that your records are kept up to date and that the medication is being used correctly. If medication is discontinued, it should be returned to the chemist for disposal.

Please remember all of your medication needs to be stored safely. If you are taking strong pain relieving medication, these medications need to be kept especially safe. A record of how often you are required to take these medications and any anti-nausea medication can assist the health care professionals caring for you to assess if your symptoms are being managed well.

There are information leaflets available to help you understand and manage any strong pain relieving medication you may be prescribed. Please ask your nurse about these leaflets.

NOTE: Not every patient will experience pain or other symptoms that require medication.

Complementary Therapies - Some patients use different therapies to complement the mainstream medical care they may be receiving. When first referred to the hospice service, patients will be asked if they are using any complementary therapies and this information will be shared with the care team to ensure everyone is fully informed. Some complementary therapies are offered at Te Rangimarie Hospice, such as gentle massage and aromatherapy.

It is always patient choice whether to access these therapies or not.

Pressure Injuries

What is a pressure injury? - A pressure injury also known as a pressure sore, bed sore or decubitus ulcer, and is an area of damaged skin and sometimes involves underlying damaged tissue. They can be painful and often take many months to heal.

A pressure injury can develop in a matter hours, if a person is left sitting or lying in one position and are unable to move themselves regularly. At first the skin changes colour, usually redder or darker. If not treated, it can become a blister and eventually develop into an open sore.

The areas most at risk are:

- the base of the spine
- bottom
- hips
- heels
- ankles
- elbows
- shoulders

These areas usually bear more body weight and the bone is closer to the skin.

Who is most at risk? - People, who have prolonged periods of time in bed, are dependent on a wheelchair or sit for long periods of time. Normally these people have restricted mobility. The elderly and weak are also at risk. Those who have poor circulation, illness or disease including diabetes, heart disease, cancer, stroke, kidney failure, incontinence, poor nutrition and/or fluid intake, have an increased risk of developing a pressure injury.

What should you do if you get a pressure injury? - As soon as you notice any skin changes or soft areas, ring your hospice nurse and ask for advice, or for them to visit and check the area. The nurse may suggest that you have a pressure relieving cushion on your chair, or a special mattress for your bed – these all help distribute the pressure more evenly and prevent pressure injuries from developing.

Remember – it is better to prevent pressure injuries, so try to keep moving and change your position as much as you can.

Reference: JBI Pressure Ulcers-prevention of pressure related damage and Best Practice, 12(2) 2008

Skin Care Advice

Check your skin daily for any signs of damage. If your skin does not return to its normal colour after you have removed your weight from it or if it is redder, bruised or blistered, please ask for advice as soon as you can. Don't be afraid to ask a carer to look for you – or you can use a mirror to see difficult areas.

Keep your skin clean and dry. Don't use talcum powder as this will dry your skin out and deprive it of its natural oils. Only use skin creams with your nurse's advice.

- Be gentle when you dry your skin. Pat it dry with a soft towel, do not rub or massage your skin – particularly over bony areas.

- If you are incontinent or having problems with toileting, ask for help – and if you do have an accident make sure you change your clothes and bedclothes if they are wet or soiled.
- Try to eat a healthy diet if tolerated – drink regularly.
- Seek advice if you have swallowing or eating difficulties.

What causes pressure injuries? - Factors causing pressure injuries can be divided into 2 groups:

Internal Factors: Disease, advancing age, under or overweight, poor skin condition, limited mobility, incontinence, poor diet and dehydration.

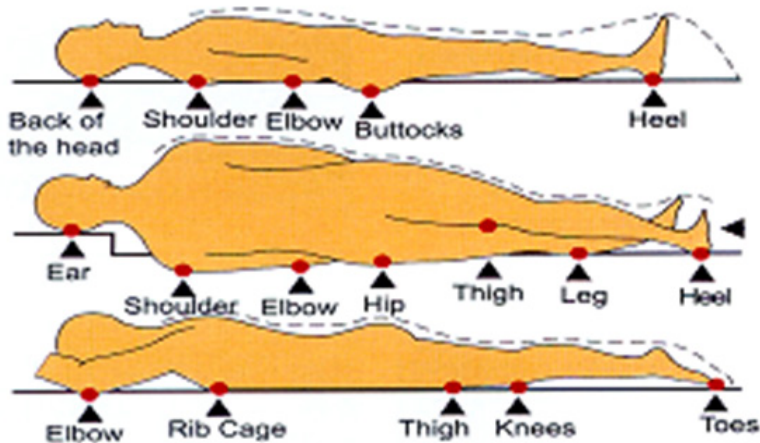
External Factors:

Pressure: This is caused by a person's weight. As a result, normal blood circulation can be affected, cells can be starved of nutrients and waste products are not removed. This ultimately causes damage and tissue breakdown.

Shear: Shear will only occur when there is pressure. It is caused when a person moves their body, but the skin remains in the same place e.g. when a person slips down in the bed but their bottom does not move on the sheet. This can be seen as a bruising or grazing on the surface of the skin.

Friction: Occurs by an abrasive action when a person is slid across a bed rather than lifted.

Practical tips to avoid pressure injuries



When Lying Down

- Change your position at least every hour, more frequently if possible, between your back and your sides.
- If you are on a special pressure relieving mattress you still need to change your position every 2-4 hours.
- When you lie on your side use soft pillows to protect your knees and ankles from touching each other.
- If you have sore heels or your skin is in poor condition, you may need heel protectors or heel rests.
- Use a lightweight duvet instead of heavy blankets.
- Try and use cotton sheets rather than synthetic materials as your skin is less likely to become hot and sticky.
- Take care to avoid lumps and creases in your bedding.

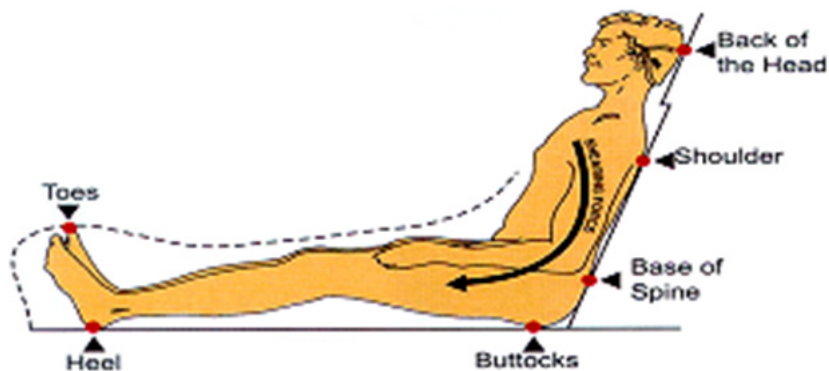
When you sit up in bed try not to slide on your heels or bottom – ask someone to help lift you up. This will prevent friction or shearing damage.

- If carers are helping to lift or transfer you, make sure they do not drag you across the bed. Ask your hospice nurse to show the best way to help lift you.

When Sitting

Try and relieve pressure every 15 minutes. Take the weight off your bottom by leaning forward while pushing up with your arms or roll from buttock cheek to buttock cheek.

- You may need a special cushion to help relieve the pressure.
- Avoid sitting in the same position for prolonged periods.



We acknowledge Morton and Perry Homecare Equipment - In the development of this information pertaining to “prevention of pressure injuries”.

Support

Our confidential service is available to the patient, families/whanau and/or significant others.

Individual Counselling

Our counsellors are qualified and belong to the New Zealand Association of Counsellors. To make an appointment please phone (06) 753 7830 ext 8669.

Couple/Family counselling

Illness and bereavement within a family can create special problems. Relationships between couples and interactions between parents and children can change. Some family members find it more difficult to talk about the illness or its effects on relationships or family life. It can be helpful to discuss these issues with a counsellor.

Counselling for Children

We recognise that counselling for children is an area requiring specialist expertise. We refer to counsellors specifically trained and who have experience in dealing with children or young persons.

Carers Support Group

This group offers the opportunity to gain the support from being with other carers whilst in a confidential environment. Amongst other topics we look at issues of self care, how to manage stress, education about the grief cycle, and care of the palliative person.

Kaiawhina (Cultural Support)

Our experience kaiawhina is available to you or anyone in your whanau who would like cultural support. Our kaiawhina can meet with you either at your home, at hospice or on the marae. You may wish to talk about your cultural and spiritual needs; our kaiawhina may be able to offer guidance around tikanga Maori (cultural practices), planning for you future care and tangihana (funeral). Our kaiawhina can help with whanau hui (meetings), karakia (prayer), waiata (song). You may want help to link you and your whanau with other Maori support services or community groups such as Marae, ministers, kaumatua. Any questions about our kaiawhina cultural support – either speak to the nurse or phone Hospice.

Practical Support

Help with practical matters is also provided. It can be important to sort out legal issues at this time and topics may include arranging a funeral, and sorting out wills and other business affairs, including eligibility for WINZ and for respite care. This group runs periodically in New Plymouth and Hawera. Groups run for six weeks and respite carers are available to be with patients at this time if required. Morning tea is provided.

Volunteer Support

Volunteers add a very valuable dimension to our organisation. The main function of volunteers is service enhancement. That is, volunteers add to the work of the paid staff, and to the experience of patients and families/whanau. People volunteer their time for a number of reasons. They may have benefited from Hospice services in the past; they might want to acquire job experience and skills: to become part of a group; to remain active; to have other interests to be a responsible part of the community. Some of the roles they perform: Transport, Community-based family support; bereavement support; biography writing, Respite sitting for patients and carers/families/whanau.

Day Programme

Without the support, help and hours worked by volunteers within these roles Hospice Taranaki would be unable to continue with this very important service to our Community. If you would like to take advantage of volunteer support please ask your hospice community nurse. Often, the diagnosis of life-threatening illness can lead to people feeling isolated. That's why Hospice Taranaki offers the opportunity to join our Day Programme. Many patients enjoy the opportunity to come along for the day to meet other people experiencing a similar situation and to take part in a wide range of activities and/or entertainment. Sumptuous morning tea and lunch are provided. It also gives carer(s) the opportunity for a break while you are at the Day Programme. The programme is based at Te Rangimarie and currently is held each Wednesday and Friday, 10am to 2pm. If as a patient you are interested in attending just ask your Community Nurse or District Nurse.

Your Life Biography Service

A biography gives patients the opportunity to tell their story. It may be your life story or memories that are important to you. Your story belongs to you, it is about the way you remember things. It can take the form of stories, letters, poetry, photos etc. You may edit or alter the biography as it is being written and you can end it when you choose. The biography is your personal property and you are responsible for deciding what to include. Hospice Taranaki Biographers will visit the patient's home at a convenient time. Your privacy will be respected at all times, and the Biographer abides by the Code of Confidentiality at Hospice Taranaki. No record of the interviews will be kept. On completion of your biography you will be presented with 4 copies. Additional copies are available at a small cost. If you are interested in recording your story you can contact the Family Support Manager at Hospice Taranaki. Phone (06) 753 7830 or ask the Hospice community nurse to make a referral.

Practical Information

Advance Care Planning

Towards the end of life people often want to put their affairs in order. One way people can do this is by preparing an Advanced Care Plan (ACP). Advanced care planning is a way to help a person think about, talk about and share their thoughts and wishes about their future health care. This makes it much easier for families and healthcare providers to know what the person would want – particularly if they can no longer speak for themselves.

As part of advanced care planning Hospice Taranaki has a “Plan of Care for Emergencies” form. This form is completed by the patient in consultation with Hospice Clinical Staff and documents the patient’s wishes should they suddenly become ill. This provides guidance for Ambulance and/or Emergency Department staff to help ensure patient’s wishes are followed. If you want to know more about Advanced Care Planning please talk to a Hospice Clinical Staff member or to your GP. You can also check out the Advanced Care Planning website: www.advancecareplanning.org.nz

Financial/legal Issues

This may include assembling important documents such as insurance policies, share certificates, bank account details, birth certificate, wills and other important documents like Enduring Power of Attorney.

If legal arrangements like Wills or Enduring Power of Attorney are not already in place, this would be a good time to action them. Individual bank accounts will be frozen once death has occurred, however joint accounts are not usually frozen. It may be a good idea to set up a savings account in the spouse or partner’s name to ensure there will be money readily available.

Enduring Power of Attorney (EPA)

There may come a time when the patient is unable to make decisions on their own. A legally drawn up EPA will allow a nominated person to make decisions on their behalf should they be unable to in respect of financial and health care issues. A Solicitor or the Public Trust Office can perform this task for a fee.

End of Life Care

End of life care is an important part of the care the palliative care team provide. Some patients may choose to remain at home at this time whereas others may choose to die in Te Rangimarie or in a residential care facility which may have been their home. Once again, the palliative care team work with the patient and family/whanau to ascertain what their preferences are and to support the choices being made. Sometimes it is not possible for a person to remain where they wish to be so alternative plans may be made to allow for this.

Hospice Taranaki has a number of information leaflets available which may be helpful for carers/family members to read. These include: "What to expect when someone is dying", "Planning for a Funeral" and "Tips for coping with Loss and Grief".

What to expect when someone is dying

The dying process is unique to each person, but there are common changes which occur that indicate that a person is dying. Most changes do not need special treatment, hospitalisation or professional help. If you are unsure please discuss this with your visiting nurse or doctor.

Here are some of the changes which may occur:

Not Eating or drinking - There will come a time when food and drink are neither wanted nor needed. This can be hard to accept but it is a

physical sign that the person is not going to get better. Caring can be continued in other ways such as moistening the lips and mouth. Ice chips or small amounts of water will do this.

Change in Awareness - As the person becomes weaker, the person will spend more time in bed and lose interest in their surroundings. The person may become sleepy and may lapse into unconsciousness. This may last for a short time, or for several days.

Breathing - It is very common for breathing patterns to change. There may be gaps of seconds or minutes between breaths, with the gaps getting longer. Secretions may cause the breathing to become noisy. It is not distressing for the person who is dying, but it might be for you. Contact the nurse for advice.

Incontinence - Sometimes there is a loss of control of the bowel and bladder. The Hospice has incontinence products available to help manage this.

Confusion/Restlessness - You may notice increased restlessness: the person pulling at bedclothes, trying to get out of bed, muddled thinking and conversations. Hospice staff can use medication to help settle a patient who is distressed by this.

Change of Colour/Temperature - You may notice the person's arms and legs feel cool and clammy. The colour may become darker or patchy. This does not mean that the person is feeling cold, but simply part of the body's process of slowly winding down.

How will you know when the person has died:

- Breathing has stopped
- No heartbeat or pulse
- Eyes may be fixed on a certain spot or slightly open
- Jaw relaxes, the mouth stays open

What do you do when someone has died:

If you are in Te Rangimarie Hospice let a staff member know. At home, you don't have to do anything straight away. Ring Hospice Taranaki (06) 753 7830 and a community nurse can visit if you wish and can

advise you on what to do next. You don't need to ring an ambulance or the police. The community or district nurse will notify the doctor for you. Contact the Funeral Director of your choice and they will assist you with arrangements.

Funeral Arrangements

It is always helpful if family members are aware of the patient's preferences in regards to funeral arrangements. Often patients plan their funeral in advance by working with a funeral director. The funeral director will be able to advise on options and costs involved. There is a grant available from WINZ which is means tested. The funeral director can provide advice if you wish to apply for this.



On-going Support

Bereavement support

Hospice Taranaki provides bereavement follow up 8 weeks and 24 weeks after bereavement. A letter is sent out to all next of kin and then our trained bereavement team will follow up with a phone call to ascertain how family members/carers are doing and if they require support. All family members and significant others can access our confidential counselling service after bereavements.

Bereavement Group - This group is for bereaved family/whanau and/or significant others of those who have received hospice care. This is an opportunity to gain the support from being in a small group with other bereaved people. During this time together there is the opportunity to reflect on your experience and look at the process of grieving and ways of coping with life as it is now. There is education about the grief cycle, the emotional, physical and social effects of grief, combined with exploration around inner resources and ways of making meaning of your experience and moving forward.

These groups are run in New Plymouth and Hawera hosted Thursday mornings for six weeks and include morning tea.

Memorial Service

Hospice Taranaki hosts memorial services in June and November in New Plymouth and November in Hawera. Afternoon tea and a time for fellowship is provided after the service. Invitations are sent to all families within 12 months of bereavement.

Is this depression?

When feelings of unhappiness are intense and persistent and they don't go away it could be depression.

Tips for coping with loss and grief - Grief can be really tough - Grief can sometimes make you feel you are going crazy - It affects how we think and feel - How we do things and our relationships with others - It can affect our body's physical - Remind yourself that "grief is normal after loss and it won't always feel that way"

- There will be good days and bad days and you will get through it
- Talk to people you can trust, let what is inside out, talk about memories, worries, feelings, thoughts and questions.
- Time out is important, find ways to chill out and relax
- It's okay smile, to laugh and to enjoy things. Life has lots of good things in it, even during tough times
- Use support around you. It's important to ask for help, even if people don't always get it right
- Don't expect too much from yourself, you're only human
- Keep safe – avoid taking risks
- Eat well and keep active
- Avoid making hasty major decisions

Signs and symptoms - Irritability and restlessness, feeling tired all the time and general loss of energy, Feelings of emptiness and loneliness, No longer interested in favourite activities, Sleep problems (too much or too little), weight loss or gain, low self esteem, problems with concentration, reduced sex drive. These signs and symptoms should be taken seriously, especially if they have lasted longer than two weeks. You can seek help from the Hospice Taranaki Family Support Counselling team by calling (06) 753 7830. You can also access information from the Skylight website www.skylight.org.nz; talk to your doctor or a counsellor; ring the Depression Helpline 0800 111 757 or visit the website www.depression.org.nz

Complaints Process

Complaints can be made verbally or in writing and an investigation will be undertaken which includes a discussion with the complainant. The complaint may be identified as an opportunity for quality improvement to the service. If this is the case the quality improvement will be implemented. Any staffs involved are interviewed and steps taken to identify all contributing factors and appropriate action to be taken to remedy the cause. The identity of the complainant and resolutions are filed confidentially, with those being advised of the outcome.

The outcome of the complaint will be advised to the complainant in writing. If you are not happy with the outcome you will be referred to the Health and Disability Commissioner. An anonymous report outlining the nature of the complaint, investigation and outcome is provided to the Board of Trustees by the Chief Executive.

The Health and Disability Commissioner's office offers a free advocacy service to assist complainants with their complaint. The Advocacy service can be contacted by phoning 0800 11 22 33 OR contact 0800 555 050 advocacy@hdc.org.nz Nationwide Health and Disability Advocacy Services.

Te Rangimarie House Rules

We welcome you to stay with your family/whanau member. Please feel free to provide as much care for your loved one as you feel comfortable with. We have put some rules in place to ensure everyone is aware of the expectations while visiting or staying over. We are very happy to be able to provide a shared space for families and whanau to use whilst supporting patients in the inpatient unit. To keep everything running smoothly, we need to ask for you to abide by some simple housekeeping rules:

SECURITY – The building will be locked after daylight hours. If you unlock any exterior doors, please ensure you re-lock the door to prevent unauthorised entry of others. Please ensure all valuables including handbags are kept out of sight as we are unable to take responsibility for these items within the facility. The exterior doors are alarmed after hours and staff will be alerted to any doors being opened. We need to remain very security conscious due to the medications kept onsite and patient, staff and family safety.

FOOD & DRINK – The local corner shop has a good range of food items for purchase. Tea and coffee supplies will be provided by the staff for your use. Please do not use the main kitchen in the Te Rangimarie. Families/whanau are welcome to prepare meals and refreshments in the kitchen located in the Yarrow Wing. Please be responsible for washing your own dishes, either by hand or dishwasher. We ask that you be considerate of others needing to use the space and ensure you clean the area after use. Dishwasher chemicals are kept in the cupboard with the 'kiddie-lock'. Please ensure this cupboard remains secure to protect small children from harm.

STAYING OVERNIGHT – Up to 3 people per patient is considered a suitable number to ensure consideration is given to other patients/families. This number is discretionary based on Te Rangimarie occupancy. Please discuss with staff if more people wish to stay. It is preferred that younger children stay offsite overnight. The shared family/whanau suite in the Yarrow Wing has beds available and extra guests may use mattresses on the floor. Ask staff about this. It would be very helpful if you stripped the beds when you left, just ask the staff for a linen skip.

CHILDREN – Children must be supervised by an adult at all times while in the Te Rangimarie.

PETS – Visits are welcome. Please keep dogs' visits to a short duration. When not in the patient's room, dogs should be kept on a lead.

HOUSEKEEPING – We would appreciate your help in keeping the Hospice areas clean and tidy. Our household chores are performed mainly by volunteers. If you are using the whanau area please ensure you keep the areas clean and tidy after use. There is a vacuum cleaner, broom, brush and shovel provided.

SHOWERING & LAUNDRY – An ensuite and laundry are located in the family/whanau suite in the Yarrow Wing. Towels are provided but family/whanau is requested to launder these in the area provided.

BATHROOM/ENSUITE- This is a shared bathroom so please ensure it remains clean and tidy. Used towels need to be laundered in the area provided. All chemicals are kept in the cupboard located adjacent to the washing machine and dryer to ensure safety for children. Clinell wipes are provided for family/whanau use to wipe toilet and basin areas, (do not flush these) Full cleaning of the shower and other areas will be performed by staff/volunteers.

PRIVACY & NOISE – As this is a shared facility used by many people, please be considerate of others needs for privacy and noise control. The call bells are silent, linked to staff pagers.

SMOKING/DRINKING – There are two designated areas for visitors' smoking; the courtyard of Iona Lounge and the outside area adjacent to the Kowhai Room. Please ensure butts are placed in receptacles provided. Please do not smoke at the front entrance. Alcohol is acceptable in moderation.

EDUCATION SUITE USE - At various times during the day, the education room may be in use for education sessions. The kitchen may be required by staff using this area for light refreshment preparation. It would be appreciated if the noise levels within the kitchen/family and whanau areas are kept to a minimum when the education area is in use.

FIRE – If the fire alarm sounds please proceed to the front reception area, and follow the instructions of the staff fire warden who will be wearing a green vest. They may ask for your assistance in getting everyone to safety. The bedroom door is a fire door and must be kept closed at all times. Please ensure lint is removed from the dryer after each load.

Staff on duty reserve the right to request visitors to leave the Te Rangimarie if considered necessary for any reason. We hope your stay in the Yarrow Suite is comfortable and would welcome any suggestions for improvements on management of this area.



Your Records

The following pages are for you.

Medication – This is for you to keep a record of your medication which your nurses or doctor will sometimes ask you to do. It is not for recording all the medications that you take.

Bowel Record – This is for recording your bowel movements if you feel that your bowels are not working as they normally do.

Notes – This is for recording any notes that you want to keep or questions that you want to ask and also for your nurse or doctor to record anything that they would like you to remember.



Medications Record

[illegible]

Medications Record

[illegible]

Medications Record

[illegible]

Medications Record

[illegible]

Bowel Record

[illegible]

Bowel Record

[illegible]

Notes

[illegible]

Notes

[illegible]

Notes

[illegible]

Hospice Taranaki



Te Rangimarie Hospice,
5 David St, Westown,
New Plymouth



Hospice Taranaki,
PO Box 5122,
New Plymouth 4343



06 753 7830



info@hospicetaranaki.org.nz



www.hospicetaranaki.org.nz





www.hospicetaranaki.org.nz