Patient and Family Information





Gallagher Family Hospice

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Hillcrest, Hamilton, 3216
PO Box 325, WMC
Hamilton 3240
Telephone (07) 859 1260
Freephone 0800 HOSPICE
Fax (07) 859 1266
www.hospicewaikato.org.nz

Our aim is to provide you care, comfort and the best quality of life possible, while providing support for your family/whānau.

Your Hospice Waikato team





What is Hospice care?

Hospice Waikato helps people who are living with a terminal illness to live life to its fullest, while providing comfort and specialist palliative care.

Hospice Waikato provides dignified, comfortable care for people who are living with a terminal illness which is active, progressive or advanced.

Anyone affected by a terminal illness, who has complex symptoms or problems that are not able to be managed by their primary care team, may be referred for hospice care.

Our services and care enable patients to stay at home for as long as possible, surrounded by the people and the things they hold dear. Our patients and their family/whānau are supported by our team of specialist palliative medicine doctors and nurses, as well as social workers, counsellors, spiritual care coordinator and music therapist.

Hospice care looks after the whole needs of a person, through medical and nursing care along with emotional, social and spiritual support. Hospice care is provided free of charge.

You matter because you are you and you matter to the last moment of your life, and we will do everything we can, not only to help you die peacefully, but to live until you die.

Dame Cicely Saunders, OM, DBE



How can we help you?

It is understandably a very difficult time when you are told your condition requires palliative care.

Palliative care is an approach that aims to improve quality of life for people who face progressive life-limiting illnesses such as cancer, neurological conditions, advanced kidney failure or heart failure.

How we can help you ...

■ We will assess and help manage your physical symptoms.

- We will help you, your family/ whānau and carers deal with the changes and challenges that lie ahead, allowing time to discuss any physical, emotional and spiritual issues.
- We provide specialist advice and information on treatments.
- We provide advice on practical issues such as financial support, referrals to other therapeutic services, and how to get help with day to day tasks, should you need it.

- We support your loved ones and family/whānau to enable them to cope during this difficult time.
- We work to assure the long-term well-being of your family/whānau.



Hospice Waikato services



Hospice@Home

For Hamilton City, Ngaruawahia, Cambridge.



Rural Outreach

In the wider Waikato, working in partnership with district nurses and GPs.



Outpatient Clinics

For specialist assessment and treatment of symptoms and problems.



11-bed Inpatient Unit

For symptom management, end of life care, and arranged respite.



Rainbow Place

Our children and young people's service.



Family Services

Emotional and social support through illness, death and bereavement including individual and group support, spiritual and cultural support and creative therapies.



Volunteer Support

For Hospice Waikato patients.

Who will provide my Hospice care?

During your illness you may have many people looking after and caring for you.

As a team we work very closely with GPs, district nurses and hospital staff as well as other health professionals. Your team may include:

- A nurse practitioner
- Clinical nurse specialists
- Palliative care nurses
- Palliative medicine doctors
- Social workers
- Counsellors
- Spiritual care coordinator
- Music therapist
- Trained Hospice volunteers

How do I access these services?

Health professionals may refer you when the complexity of your illness is such that specialist assistance is needed to control your symptoms and provide social, psychological and spiritual support to you and your family/whānau.

You may self-refer, though we will request permission to confirm your diagnosis and medical information with your GP or specialist.



Hospice@Home

Hospice@Home services are offered within Hamilton City, Ngaruawahia and Cambridge. On your referral, a registered nurse, skilled in the holistic care of patients who have a life-limiting illness, will be assigned to co-ordinate your care.

We aim to provide compassionate and skilled palliative care in collaboration with your family/whānau.

This care is primarily provided within your own home; it also includes support if you are in residential care.

Care includes:

- Assessing your needs and working with you and your family/whānau to develop individual plans of care.
- Help with symptom management.
- Support and education for you and your family/whānau regarding ongoing care requirements.

- Communication with other health professionals such as your general practitioner and/or specialist.
- Referral to other services e.g. home help, personal care and respite care.
- Assisting and coordinating referrals to residential care or hospital level care facilities if required.
- Arranging equipment to aid home care, as it is needed.
- Providing ongoing emotional, social and spiritual support in collaboration with the Hospice Waikato Family Services team.

■ Connecting you with skilled support volunteers who are able to spend time listening in a warm and supportive way if you feel this would help.

Hospice@Home hours

The Hospice@Home nursing team is available for in-home visits Monday to Friday. There is an urgent on-call overnight service for patients already under Hospice care seven nights a week. Please call our main telephone line for this service - 07 859 1260 or 0800 HOSPICE.



Rural Outreach

Hospice Waikato's Rural Outreach service is for people with specialist community palliative care needs who live outside of the Cambridge-Hamilton-Ngaruawahia area. It provides specialised medical, nursing and family support, in collaboration with district nurses, general practitioners and other health providers.

Our Rural Outreach team includes a nurse practitioner, a clinical nurse specialist and a team of palliative care nurses, as well as a visiting palliative medicine doctor.

The Rural Outreach team works with district nurses, general practitioners and other health services to provide care and support for you and your family/whānau.

What does Rural Outreach care include?

- Outpatient clinics and home visits for specialist palliative care assessment and advice.
- Home visits for emotional, social and spiritual care and support.

- Loan of equipment for use in your home.
- Liaison with district nurses, GPs and other health services to plan and co-ordinate your care.
- Bereavement support for family/ whānau.

Our Rural Outreach service does not provide in-home clinical patient care (such as medication administration, syringe driver pumps, wound care, etc). This type of care is provided by the Waikato District Health Board District Nursing Service.

Palliative care outpatient clinics are held at provincial hospitals on a regular basis and appointments can be discussed with your Rural Outreach nurse.

Rural Outreach hours

The Rural Outreach team works Monday to Friday 8am to 4.30pm.

Outside of these hours your GP and district nurse are usually the best people to contact for care and advice, or in the case of an emergency call 111.

If you are unable to contact your district nurse or GP, Hospice Waikato provides a telephone service offering advice and guidance.

Please call our main telephone line for this service - 07 859 1260 or 0800 HOSPICE



Outpatient Clinics

Hospice Waikato runs an outpatient clinic service at the Gallagher Family Hospice on Cobham Drive.

At outpatient clinics, patients can be seen by a doctor and nurse for specialist assessment and management of symptoms and other problems, and they can also see staff from our Family Services Team. This can include a one to one appointment with a doctor, nurse, counsellor, social worker or other health professional.

At all times we work in collaboration with your GP and any other health professionals involved in your care and we will keep them informed of the outcome of these consultations. Our doctors are also available for telephone consultation with general practitioners, oncologists and other specialists.

What are Outpatient Clinics for?

Outpatient Clinic appointments are usually for an introduction to Hospice services, symptom assessment and management, follow up reviews and/or discussion about social and emotional concerns.

Some of the things that can be discussed include:

- Pain assessment and treatment
- Symptom control
- Review of medical situation
- Advice on treatment planning
- Nutritional advice
- Advance Care Planning
- Social and financial concerns

- Introduction to the day programme
- Admission to Hospice Inpatient Unit if necessary

How do I get Outpatient Clinic appointment?

Clinic appointments are usually requested by a GP or other health professionals involved in your care by contacting Hospice Waikato.

Our outpatient clinic also provides some same day procedures, such as pamidronate infusions and ascites drainage, as well as lymphoedema assessment and management.

The Outpatient clinics usually run Monday, Tuesday and Friday between 10:00am and 3:00pm.



Inpatient Unit

Hospice Waikato has an 11-bed Inpatient Unit (IPU) at the Gallagher Family Hospice on Cobham Drive in Hamilton. Patients can be admitted for complex symptom management, respite care, and end-of-life care.

Care provided in our Inpatient Unit is different to treatment provided in an acute hospital. Our focus is on managing symptoms and improving quality of life, rather than interventions.

Our team includes specialist palliative care nurses and doctors and is determined by your needs. Patients also have access to the wider Hospice team which includes social workers, counsellors, spiritual care coordinator, music therapist and massage therapists.

Our team is committed to providing holistic care and respecting your cultural and spiritual needs.

Our skilled professionals provide clinical support with care and compassion. Time spent identifying the needs of you and your family will help ensure that your treatment and care is the best possible. This approach is central to our philosophy.

Our rooms are private and spacious, each with its own en suite, TV, and outdoor area. Lounge areas with kitchenettes are available for use by patients, family/whānau and friends.

The length of your stay is decided on an individual basis with most patients returning to their own homes. Our Inpatient Unit does not provide long-term care.



How can I be referred to the Inpatient Unit?

Hospice patients may be referred to the IPU by their general practitioner, specialist doctor or community nurse. Requests for admission are individually assessed.

Reasons for admission

You may be admitted for:

- Symptom management review and control of troublesome symptoms.
- Respite care a planned, prebooked admission to allow timeout for patients, carers and family members. Admission, though booked, cannot be automatically assumed and is dependent on bed availability and will be prioritised according to patient need.
- Care in the final days of life. In some situations, care at home is no longer possible and it may be more suitable for a patient to spend their last days in the care of Hospice Waikato Inpatient Unit. This is decided in full discussion

with the patient, family/whānau and community team including the GP.

Most admissions to the Inpatient
Unit are planned in advance and can
usually be arranged within a few days.

My inpatient stay has been arranged. What do I need to do?

- Pack a bag with some comfortable casual clothing as well as your nightwear and dressing gown.
- Please bring your own medications.
- Don't forget your toiletries.
- Bring continence products if you are using them.
- You are welcome to bring family photos and mementos but please don't bring valuables.
- All bedding and linen is supplied but you are welcome to bring a favourite pillow, quilt or similar.
- Cell phones and wireless laptops can be used in the Inpatient Unit at your own risk.

How much will it cost me to stay?

It will not cost you anything to stay in our facility. However you may be charged for certain drugs that are not funded. Hospice Waikato does not meet the cost of transfer by ambulance to and from the Inpatient Unit and your home.

Visitors

Our main visiting time is between 10am and 5pm, however visiting hours are flexible as long as visitors are considerate of other patients.

This may mean that staff will ask you to restrict visitors at certain times. Family staying overnight is limited to two people due to space and security.

Please remember that Hospice Waikato site is a smoke-free environment.



Rainbow Place

Rainbow place offers compassionate care, tailored specifically to you and your child's needs.

Hospice Waikato is the only New Zealand Hospice to offer a specialist child-focused palliative care service.

Rainbow Place is where children, young people and their families/ whānau can find care and support throughout this most difficult time.

We understand that your life has changed. Caring for a child with a life limiting illness or terminal condition changes a family's life forever, it's exhausting, rewarding, sometimes positive and often painful.

Your Rainbow Place team will be with you as you undertake this journey, offering advice and support as you require.

Our Rainbow Place team offers specialist nursing care and Family Support Services, from emotional support to relieving physical symptoms, our team will advocate for your family to have the support required to be able to enhance the time your family has together.

We visit in your home, hospitals and community (e.g. schools, marae) and coordinate the care of your child, working with all health care professionals involved while acknowledging that parents and caregivers know the child best.

Rainbow Place also offers of respite care. This helps to ensure the whole family/whānau get the support (and sleep) needed.

Our comprehensive package of care for sick children and young people also includes counselling and therapeutic support for family members and carers.

All services are provided at no charge.

Who can be referred?

- Children and young people affected by the serious illness of a close family member who is under the care of Hospice Waikato adult services.
- Children and young people who have a serious life-limiting or life-threatening condition.
- Children and young people affected by the sudden or unexpected death of a close family member (as resources and staff availability allow).



Working in partnership with families and whānau, Rainbow Place provides specialised nursing care for children and young people in the community, at home, in school and in hospital.

What is a life-limiting or life-threatening condition?

A life-limiting or life-threatening condition is an illness where the child or young person is either not expected to live far into adulthood, or their condition may result in premature death.

This may include:

- Life-threatening conditions for which curative treatment may not be feasible, for example cancer, irreversible organ failure
- Conditions where premature death is inevitable, for example Cystic Fibrosis, Duchenne Muscular Dystrophy.
- Progressive conditions without curative treatment options, for example Batten Disease.
- Irreversible, but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of

premature death, for example severe cerebral palsy, severe brain injury.

Who can refer?

- Families, friends and relatives
- Healthcare professionals
- Schools
- Social services

Support is available at Rainbow Place, in the home or in other community settings, e.g. schools, marae.

The Rainbow Place Family Services team offers

Children and young people suffering from life-limiting illnesses or grief, often find it hard to put their feelings into words. Through our music, art and play therapy we hope to increase happiness, responsiveness and empowerment for these children and their families/whānau. Our Family Support team will work closely with your family, throughout the care of your child including providing

ongoing bereavement support. Our therapists, social workers and spiritual care coordinator offer opportunities for parents and children to discuss and explore the emotional, social, spiritual and practical issues that are integral to caring for a child who has a progressive and life limiting illness (or who is suffering from grief and loss).

Our services include:

- Multi-disciplinary team approach
- One-on-one counselling
- Group workshops
- Family therapy
- Support groups
- Art therapy
- Memory-making activities
- Sandplay therapy
- Child-centred play therapy
- Directed hospital play
- Music therapy
- Massage
- Parent and carer support groups
- Inpatient respite care in IPU Rainbow Place room.



Family services

Supporting families/whānau through the journey of change, loss, grief and bereavement.

Coming to terms with serious illness and dying can be difficult and distressing for all concerned.

When someone is seriously ill, everyone around him or her is affected. The patient and family/ whānau may deal with a whole host of emotions, from anger to helplessness, fear or depression.

Through our Family Services team, Hospice Waikato provides patients and families/whānau with an opportunity to identify and deal with the emotional, social, and spiritual impact of terminal illness. The team includes counsellors, social workers, spiritual care-coordinator and a music therapist.

Counselling

Often the emotional pain and stresses associated with illness or death can be as difficult to deal with as physical symptoms.

Hospice Waikato offers professional counselling services for patients and families facing illness, death and bereavement.

Counselling is a process that offers you an opportunity to safely explore your thoughts and feelings.

Our counselling service is free, confidential and available to all Hospice clients and their family/whānau.

We also offer telephone counselling to support families living in rural or remote areas of the Waikato.

Social Work

Our social workers are here to help you through illness, bereavement and the changes that you will be facing.

A social assessment assists to identify areas of need and possible solutions.

We are able to help with:

- Access to resources, social and community support networks
- Knowledge of your entitlements
- How to manage financially
- Housing including residential care placement
- Advocacy, e.g. with Work and Income
- Exploring options for immediate needs and long term planning, e.g. advance care planning
- Legal aspects, e.g. making a will and setting up powers of attorney
- Funeral planning
- Family meetings



Family services continued

Spiritual care and support

Spiritual care and well-being is an integral foundation of all hospice care. It is provided by all staff in their many and varied ways of caring for you and your family/whānau. These important roles are supported and assisted by our spiritual care coordinator who is present and available to you upon request.

Hospice offers holistic care to patients, family/whānau and caregivers. It is founded upon attention to your personal, religious, spiritual and cultural values.

Spirituality and culture shape who we are and how we live. Our commitment to Te Tiriti O Waitangi is reflected in our care for whānau and families according to their own unique spiritualities, cultures and faith traditions.

Music Therapy

Music is something that touches us all, it can provide comfort and support through difficult times and gives a voice to those feelings that words alone cannot describe.

Music therapy is available for adults, children or young people at Hospice Waikato. It has been found to be beneficial in palliative care and also when people are coming to terms with change in their lives through illness and bereavement.

Bereavement support groups

Bereavement groups are recognised as an effective way to promote healing through learning with others and mutual support after the loss of a loved one or close friend.

Bereavement follow-up

We have a range of counselling services that are available for patients and family/whānau during your illness and family bereavement.



Family services programmes

You are warmly invited to attend any of our programmes for patients and family/whānau. Our hospitality areas offer tea and coffee.

Please feel free to talk to your nurse about the options available.

If you are coming in, please phone 07 859 1260 or 0800 HOSPICE to let us know beforehand. We look forward to seeing you.

Our programmes include:

Monthly 'welcome to Hospice' session

Hear about the services Hospice Waikato offers you and your family/ whānau. See our facility and have your questions answered.

Creative space

You can have a one-to-one session with a counsellor / creative therapist in the comfort of your room, or a group / family session.

The Hospice art programme provides a space for the experience of illness and

end-of-life concerns to shift, however briefly, into the background.

Creativity is a fundamental life force, whether you express your own or find something that touches you — a painting, a handmade card, or a decoupage.

This programme offers you the opportunity for relaxation and self-expression.

It also offers you the opportunity to replenish your spiritual soul and inner artist and to leave a lasting, tangible legacy.

All patients, and their family/whānau and friends are welcome.

This service is available any day on request. If you wish to attend any of these programmes please phone reception on 07 859 1260 or 0800 HOSPICE.

Patient and carer creative therapy support group

This is a group for support, time to yourself, telling stories and making memories, self-expression, questions, or concerns. Express yourself through mosaic making, decoupage, paints and pastels. All patients and their carers are welcome. You are welcome to stay for all or part of the day.

Relaxation hour

In those moments when we feel the tension rise, knowing some simple relaxation and meditation techniques can offer a helpful way through.

Patients and family members are invited to attend the relaxation hour.

Please note this is by request only.





Volunteer services for Hospice patients

Volunteers are essential to the delivery of Hospice care. Working alongside Hospice staff, volunteers enable us to provide a number of additional services for patients and their family/whānau. Our volunteers are trained to provide these services with compassion, dignity and respect.

Hairdressing

Perhaps you are finding it difficult to get to the hairdresser, or simply can't spare the time away. We have a hair cutting and styling service in our Inpatient Unit on Wednesday afternoons for patients and carers. Wet cuts, dry cuts, styling all inquiries welcome. A mobile service may be available in some areas.

Massage

Relax and unwind with a massage of vour choice.

Massage is an excellent way to relieve stress and release tension, allowing your body to relax and rejuvenate. You may like to choose a gentle touch massage, a full body massage, or just focus on tension areas like your back, neck, and shoulders, feet or hands. Seated massage - using a forward sitting chair, the massage focuses on the upper back, shoulders, neck and upper arms. This therapy produces exceptional results while allowing you to remain fully clothed and seated

upright, or there is an adjustable height electric bed available for patients requiring this facility.

Life Review Service

- making a memory book

Recalling special moments in your life and capturing these into a story, a story about you, which will become a treasured record for future generations. They will want to know about the people you have met, places you have been and experiences you've had.

What is involved?

A trained volunteer will visit, interview and record your story in your own words which may be made up of memories, photos and poems. Or you may wish to write it yourself. If so, the volunteer will help as required. These visits usually last about an hour. Once the interviews are complete, a transcript will be typed and given to you for proofing and editing. Once approved, your completed story will be bound and given to you to keep and share.

Who sees this story?

You decide whether this story is just for you or whether you wish to share it with family and friends.

What about confidentiality? Each volunteer signs a confidentiality agreement promising that all information about you and your family is strictly confidential and not discussed outside Hospice Waikato.

What about the cost?

There is no charge for this service. You will be provided with one bound original and an electronic version, if required, at no cost to you.

How do I get this service? This service is available by contacting Hospice Waikato or your Hospice Waikato nurse on 07 859 1260 or 0800 HOSPICE.

Family support

Caring for a loved one during this time can be very tiring. Hospice Waikato Family Support volunteers may be available in your area to visit and spend time with the patient, giving carers valuable time out.

Visits can be for companionship and can include outings when appropriate or activities to suit the individual.

This service is available by contacting Hospice Waikato or your Hospice Waikato nurse on 07 859 1260 or 0800 HOSPICE.

Your rights, privacy and confidentiality

We welcome your suggestions, compliments and complaints

Fill out a "Happy or Unhappy About Our Services?" pamphlet — available from Hospice Waikato staff members or by writing to Hospice Waikato, PO Box 325, Hamilton.

If you need advice or support from somebody not associated with Hospice Waikato about making a complaint, you can contact the Health Consumer Service, PO Box 15019, Hamilton or phone 07 846 1991 or you can write to the Waikato Health & Disability Advocacy Trust, PO Box 1256, Hamilton. Phone on 07 834 3960 or you can contact the Health & Disability Commissioner on freephone 0800 11 22 33.

Your health information may be disclosed to:

- Another Hospice Waikato professional involved in your care
- Another health agent involved in your care
- Other agencies as required or permitted by law, such as notification of infectious diseases
- Students undertaking health care studies who are involved in your case
- Another person you have agreed may see your information
- Accident Compensation Corporation (ACC).

Accessing your own health information

You can access your own health information by contacting the Hospice Waikato Privacy Officer, PO Box 325, Hamilton.

If you believe your information is not correct ask the Hospice Waikato Privacy Officer to address the matter. If you decide not to disclose certain information, then you need to be aware that this may affect your health professional's ability to correctly diagnose and treat you. Hospice Waikato is required by law to keep your health information for a minimum period of ten years from the last day treatment or care was provided to you. Your health information will be kept in a safe and secure place.

Informed Consent

Before providing any care, staff will make sure you are fully informed about what is likely to happen. You will be asked to agree to a care/ treatment plan. You may refuse care, but staff will explain the possible risks. You may always ask for more information.

Your rights

This is an outline of the rights guaranteed by the Code of Health & Disability Services Consumers' Rights.

Respect

You will always be treated with respect. This includes respect for your culture, values and belief as well as your right to personal privacy.

Fair treatment

No one should discriminate against you, pressure you into something you do not want, or take advantage of you in any way.

Dignity and independence

Services should support you to live a dignified, independent life.

Proper standards

You have the right to be treated with care and skill, and to receive services which reflect your needs. All those involved in your care should work together for you.

Communication

You have the right to be listened to, understood and to receive information in whatever way you need. When it is necessary and practical, an interpreter should be available.

Information

You have the right to have your condition explained and be told what your choices are. This includes how long you may have to wait, an estimate of any costs, and likely benefits and side effects. You may ask any questions to help you be fully informed.

It's your decision

It is up to you to decide. You can say no or change your mind at any time.

Support

You have the right to one or more persons to give you support in most circumstances.

Teaching and research

All these rights also apply if you agree to participate in teaching and research.

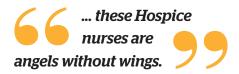
Complaints

It is OK to complain — your complaints help to improve services and will not affect the way you are treated.

Privacy and confidentiality

The health information you give will be used for:

- Your care and treatment, including follow-up care and support
- Administration related to your health care
- Monitoring the quality of your care (clinical review)
- Customer satisfaction surveys (your name and address may be used so we can send a questionnaire to you)
- Meeting our contractual obligations
- Training students in health courses
- Research purposes as permitted under the Health Information Privacy Code 1994 and Hospice Waikato requirements.



Thank you for all you did for my mum when she was in your care - bless you special people so much.

I enjoy getting to know the others in the group and reflecting with people that really understand what you are going through. We don't often cry, but definitely laugh.

Having Hospice Waikato and Rainbow Place involved has made it so much easier to cope.

What worries me the most is losing my independence and not being able to stay at home, but the Hospice staff have been amazing.

Just to know that there is someone close at the end of a telephone for guidance and support is invaluable. These include help and advice with medications especially to do with pain control that make life a lot easier for both of us. Also the hugs - cannot underestimate those.

Comments from Hospice Waikato patients



Your notes		

Hurinia to aroaro kit e ra tukuna to atarangi kia taka ki muri i a koe.







