



# The History of Lake Taupo Hospice

----

The History of Lake Taupo Hospice is the story of how so many dedicated, generous and compassionate people contributed towards providing our town with the outstanding community-based hospice we presently have in Taupo.

We are part of the Lake Taupo Hospice team of biographers and our aim has been to record the story of the hospice and to pay tribute to everyone who has worked so relentlessly for such a wonderful cause. We have mentioned many people by name, but there are so many more of you who have worked quietly in the background doing all sorts of jobs without acknowledgement. We salute you and apologise sincerely to anyone who we may inadvertently have missed.

Particular thanks go to Shona Bleakley for doing a great job with the proof reading. Thanks too to all those we have interviewed for sharing their stories and memories. We loved hearing them. We are grateful to Lake Taupo Hospice who generously allowed us unlimited access to their records and photographs. We have tried our best to be completely accurate and apologise for any errors which may have slipped into this document.

Writing this book has been a voyage of discovery for us both and we have been so generously helped in many ways by so many people. From Peggy Donaldson and her dedicated team who started with an idea, to everyone who made Lake Taupo Hospice what it is today, your commitment, enthusiasm, expertise and perseverance have inspired and motivated us. Thank you.

Jane Fogden Hélène Everest

---

# Contents

Glossary	3
The Beginning	4
The First Five Years	8
Memories of a Home Support Team member	14
The Nineties	18
Evolution	28
Hospice Education Programmes	32
The Restructure	36
Te Nohanga Kotahitanga o Tūwharetoa Iwi Health Governance Trust Inc.	42
Challenges	46
Turangawaewae - 7 Sunset Street	50
Consolidation	52
Role of the Palliative Care Co-ordinator	58
8 Puriri Street	66
Volunteers	68
Tuesday Club	73
Bereavement Programme and Kowhai Group	79
District Nurses	82
Living Every Moment	86
Strategic Plans	91
Hospice Shop	98
Creative Catwalk	103
Changes for the Future	10405
Day Stay and Bucket Lists	110
Lake Taupo Hospice Development Trust Formalised	116
The Expansion	120
Izard Hospice House	126
2015 - 2016	131
Looking to the Future	133

# Glossary

HHST	Hospice Home Support Team
HSS	Home Sitter Service
HVIH	Hospice Volunteers in Home
LDHB	Lakes District Health Board
LTH	Lake Taupo Hospice
LTHDT	Lake Taupo Hospice Development Trust
LTHT	Lake Taupo Hospice Trust
TCHT	Taupo Community Hospice Trust
TFOH	Taupo Friends of Hospice
TNKOTH	Te Nohanga Kotahitanga o Tūwharetoa

## The Beginning

#### Peggy Donaldson

"My father died when I was 14 years old, after a five-year battle with cancer. Dad's body never left home. The undertaker came to the house. He lay in state in our lounge. The funeral service was conducted at home and then the funeral procession left for the cemetery. My mother and I did not go. Women and children did not go to the graveside much then, but my five older siblings went.

Four years later my mother died while I was a student nurse. In that 'side room' there were no chairs, no cuppas during the long night and hastily her body was taken to the morgue, thence to the undertakers. We did not see her again.

Why do I tell you this? Because I think then the seed was sown. That the difference in the two family deaths impressed upon me that the care of the dying and their family was so important.

In 1981, I read an article by Dr Turbott (in the Listener) in which he spoke of Dr Richard Turnbull's work at the Te Omanga Hospice in Lower Hutt. I wrote to Dr Turnbull who said that if I was really dedicated to proceed with the plans for Hospice Care, I should organise a group to attend the Palliative Care conference in Gisborne. I was keen as I had by now spent a week at Te Omanga Hospice with my brother Duncan (Snelling), who was terminally ill. His dachsie, Tumelo, came with us.

'I had a dream'. I approached the Council and the churches for interest and funding, but no interest. My dear friend, the late Gordon Melville, took the matter in hand and the dream soon became a reality.

Gordon obtained funding for five local folk to attend the Gisborne Conference in 1982. There was Gordon, Boo Gunn, Maurice Woods, Sister Keinan and myself. It was the best conference I have ever been to. Dr Carstens of Gisborne had a wonderful and talented group of folk. They had a Palliative Care Ward at Gisborne Hospital and a very strong Home Service with Sister Frost ably at the head and a Chaplain, Lenore Briant.

This was our beginning. At times it was a struggle to convince doctors and the public that we weren't just a group of good-doers with no expertise. Finally, however, our Trust was formed, volunteers trained, Friends of Hospice formed, and we were away.

So many people did so much hard work and how do you thank them? I think they got their reward from the patients and families they cared for. Our patients are our inspiration."

And so, Lake Taupo Hospice and Peggy's dream began to take shape. Her vision was for a 24 hours-a-day, seven-days-a-week service by volunteers, which would offer comfort and assistance to the families of the terminally ill. Volunteers would give practical help and care for those patients who wanted to die at home. They would provide comfort and care to the carers, with night companion services which would enable caregivers to sleep without interruption, and day care services to enable caregivers to attend to business or have some much-needed respite. The aim was to help the relatives and give them relief from the constant care at home.

In 1981 the Hospice movement was beginning to develop in New Zealand. One of these hospices, Te Omanga in Lower Hutt, was developing into a home-based community service, with training programmes for doctors, nurses, social workers, physiotherapists and occupational therapists. The aim of Te Omanga was to allow the patient to live actively until he or she died and to let that dying be comfortable and with dignity, preferably within the patient's home. This would involve a continuing care programme which would discard the practice of moving the patient to the hospice and replacing it with a policy of taking health care personnel and facilities to the patient.



The Palliative Care Conference was held in Gisborne in June 1982 and five dedicated people from Taupo attended. The conference proved to be inspirational, enlightening and the motivation the group needed to get their dream to a reality. In a city the size of Gisborne, and with the cooperation of the hospital, they found that a Home Care group was all that was needed. As the Taupo area was smaller, the group established a scheme modelled on the Gisborne group.

Peggy Donaldson communicated with Dr Richard Turnbull regarding setting up a hospice in Taupo. He suggested that the first step that was needed was to conduct a study to define the local problem in Taupo. Taupo then had a small population and the numbers of terminally ill needing help was likewise small, hence it did not justify an inpatient unit. In order to conduct such a study, they would need to clearly define their goals, and in particular, the type of patient with whom they wished to be involved, and whether they required a care unit for the elderly or the terminally ill. Dr Turnbull cautioned that geriatrics and terminal care made a poor mix. He also felt it very unlikely that they would receive any hospital board or Health Department financial support.

He suggested that they appoint a doctor who had significant interest and experience in terminal care and who was prepared to give a large amount of time to the project. The group set about a feasibility study and designing a programme for a hospice in Taupo. In the interim, in 1984, Rotorua established a new hospice programme.

In 1986, four years after the Gisborne Palliative Care Conference and a frenzy of work, a Taupo Community Hospice Trust was formed to help patients and their families cope with terminal illnesses. The chairman of the Trust was Dr Adrian Webb and the secretary-treasurer, Gordon Melville. The Waikato hospice movement had provided invaluable support and advice to those organising the Taupo service. Initial Trust Committee Members were Mrs L. Burdett, Mrs P. Morrison, Mrs. S. Fox, Mrs. P. Donaldson and Mrs. J. Loughnan.

A bank account was opened with the Bay of Plenty Savings Bank and the signatories were Dr A. Webb, Mrs P. Morrison and Mr G. Melville.

The main item for discussion at the Taupo Community Hospice Trust meeting held on 29<sup>th</sup> August 1985 was the training programme for "home sitters". The preferred option to proceed was to have an inaugural meeting at which all interested persons would be encouraged to attend to learn about the hospice movement. The training would start soon after that date so that those interested could retain the impetus and perhaps involve others.

"Following general discussion on the preferred type of person as a 'sitter' it was agreed that prime qualities would need to be — available time, a vehicle, reasonable health, the ability to cope with potentially distressing situations in households, and — to quote — 'an ordinary person, independent, sensitive, offering support without judgement'".

The Trust held a public meeting on the 8th October 1985 at the Taupo Women's Club to explain the role of a community hospice. Guest speakers at this meeting were Sister Margaret, the co-ordinator for the Mary Potter Hospice in Wellington, and the bereavement officer, Max Cavitt. Those who attended the meeting were invited to form a Friends of Hospice Group and volunteers were encouraged to join the Home Sitter Service.

The Trust formed the Taupo Friends of Hospice group (17 founder members had been listed) to provide support for the Hospice. It was based on a Hamilton model and four observers spent a day in Hamilton at the Waikato Community Hospice Trust learning about their work.

Through membership, donations and fundraising, finance would be provided to purchase sheep skins, beds, air cushions, liquidisers and other necessary equipment. Petrol vouchers were allocated to the volunteers when they were caring for patients. Donations were being received and the Taupo Friends of the Hospice applied to become an incorporated society for tax-deductibility of donations.

The Hospice Volunteers in Homes (HVIH) was also formed. An initial training programme was organised by Jenny Pehi. Four volunteers attended a training programme at the Waikato Hospice Trust programme for home-sitters. After the initial training of volunteers in Hamilton, the Taupo hospital charge nurse, Mrs Laurie Burdett, assumed the responsibility for organising future training sessions. Volunteers for the Hospice Home Sitter Service were required to attend four training sessions which were held in the Taupo General Hospital Library. The courses usually conducted by one of the district nurses, offered listening skills with emphasis on grief and bereavement, and practical skills which covered basic nursing skills, patient care and use of hospice equipment.

At the committee meeting held on 4<sup>th</sup> November 1985, it was reported that the total number of members of the Friends group was 22.

The Lake Taupo Hospital made two single rooms available for patients where it was impossible to manage the patient at home. There was a stable foundation on which to build this dream!

#### The First Five Years

The original Trust Deeds were signed on the 8<sup>th</sup> July 1986, becoming the Taupo Community Hospice Trust. Dr Adrian Webb, the Settler for the Trust Deed, was the chairperson of Trust, the secretary/treasurer was Gordon Melville and the trustees were Gary Chapman, Paul Burdett, Jim Ridley and Pat Morrison.

On the 7<sup>th</sup> of August, a special meeting of the Taupo Friends of Hospice Society (TFOH) was held to form the new group. Thirty-eight members and friends attended this meeting, and by August 1986, 52 members had paid subscriptions and/or donations, amounting to a total of \$4,575 after expenditure. An annual membership subscription was fixed at \$5, and with the funds received from subscriptions and donations, there was \$4,000 to invest as a Trust Fund. An account was opened with \$400 for the Friends, as they were the link between the Trust and the volunteers.

Gordon Melville was elected chairperson, with Jan Cook as secretary, Vicki Quigg as treasurer, and Pat Bradley, Merril Ridley, Peggy Donaldson, Boo Gunn and Iva Sakaria formed the committee.

A group of eight women were trained by Jenny Pehi who co-ordinated other workshop leaders, such as the hospital staff who took a session on nursing skills and the undertaker who led a session on death and the burial process. These volunteers, women who were capable, compassionate and many with families of their own to care for, formed part of the Hospice Home Support Team. (HHST) The knowledge that the Home Support Team was on call reassured patients and filled a real need in the community.

"We did quite a bit of training and sitting with patients. I remember sitting with one lady and she was just lying there. I asked her husband if she minded me sitting there but he said that she would rather have someone be with her than be by herself. Sometimes there were tricky things we had to cope with." (A volunteer)

By 31st March 1987, the Taupo Friends of Hospice was an incorporated society and growing. New referrals were coming in and more volunteers were being trained. A programme of events was organised to help bring in funds and assist as public relations events. An informal Wine and Cheese evening held on 17th October 1986 was well attended, and a fashion parade organised by Trixie Tindall of "She" Intimate Apparel held on 1st May was another great success. Donations were also received via a donation box placed in the church foyers at funerals.

Then there was A Portuguese Affair organised by Merril Ridley in August 1987.



Gail Condor and Carolina Young of Auckland's Portuguese Trading Company

Held in the old Auckland Glass building in Heuheu Street and launched by the Portuguese ambassador, about 90 people attended the exhibition's opening night which showcased imported handpainted china, marble and embroidered table linens. Over the following weeks many more visitors enjoyed coffee and shortbread and the opportunity to browse and buy from the wide range of traditional Portuguese goods available. With Rugs Oriental providing Persian rugs and wall hangings to compliment the china, and 10% from all

sales of goods sold going to the Hospice Trust, this was truly an affair to remember.

Meanwhile, two co-ordinators Pat Morrison and Kate Galletly, had been elected. All the organising and administration was done through private homes as Hospice did not have their own premises to work out of or for storage. The Hospice Home Support Team (HHST) had begun to develop and become an integral part of the team that supported families of the terminally ill.



Patricia Morrison and Kate Galletly

The Friends had joined Hospice New Zealand and two of the Hospice Home Support Team co-ordinators attended their AGM in 1987. On several occasions Taupo Hospice was represented at various Hospice co-ordinators' meetings. This was vital in providing valuable information and contacts. In addition, it provided useful information on new procedures and aids to assist the terminally ill.

Newsletters were sent out to the local Friends members, keeping them informed of activities, as well as the Waikato, Rotorua and Whakatane Hospices. These newsletters were typed on an old typewriter and taken off to be photocopied. They were then dropped into letterboxes and sent by mail, and even sometimes delivered by one of the committee members on her trusty bicycle to keep expenses down. By 1988, there were 90 Friends, 21 volunteers in the HHST team, with both groups under the umbrella of the Taupo Community Hospice Trust and its six Trustees.

The Friends committee were a very dedicated group of women from different backgrounds and with a variety of skills. They held their meetings in each other's homes and built wonderful friendships over the years. Their energy went into raising funds to purchase much-needed equipment and promoting awareness in the community of the service that hospice provided. Their fund-raising morning teas held at various homes around Taupo are still remembered today as being enormous fun. In spite of the work involved in the organisation of these teas, the enthusiasm and generosity of the committee and the hostesses helped to boost both the profile and the funds of Hospice.



A group of Friends of Hospice helpers from left: Peggy Donaldson, Judi Smith, Marie Clarke, Iva Sakaria

Taupo Community Hospice Trust then published a pamphlet outlining the functions of their service to the community. It was written in both Maori and English to publicise to the residents of Taupo what Hospice had to offer. Two hundred and fifty pamphlets were distributed in Taupo to doctors, the Hospital, District Nurse, Public Health Nurse, chemists, churches, community organisations and the Information Centre. The media were also helpful in creating awareness of the work being undertaken by the hospice.

Peter and Jillian Wallers designed a beautiful new logo for Taupo Hospice, a symbol of the care and concern that Hospice stands for. They were made honorary members of the Friends of Hospice in recognition of their work. Taupo Hospice now had an impressive official logo and letterhead.

At the AGM in 1988 a new Friends committee was elected and Merril Ridley took over as chairperson following the resignation of Gordon Melville.

"We came to live in Taupo in 1974. Both Jim and I were on the Board of Trustees of Taupo Hospice many years ago. I became involved with Hospice both through Peggy Donaldson and my work. I am a podiatrist and had my own practice here for 37 years. I was very involved with the Health System and for the first 17 years, I was the only podiatrist in Taupo. I used to visit all the rest homes and was often asked to do house calls too. I was always happy to do those as I could see that there was a need for terminally ill people to be looked after in their own homes. Invariably every one of us is touched in some way by a terminal illness."

Merril Ridley

Ongoing training for the volunteers of Hospice Home Support Team were undertaken, one being "Introduction to Listening and Helping Skills" which greatly assisted the volunteer support through the grieving process.

The Friends were able to assist a small group set up a Breast Surgery Support Group in Taupo. Several women's groups prepared meals and baking for families in care. Simple meals such as soups, fish pies and casseroles were welcomed. During a strike at Taupo Hospital in 1988, hospice workers helpfully served supper at the hospital and looked after the flowers.

Initially, equipment comprised of commodes, food processors and bits and pieces. Baby monitors were a breakthrough in those early days. They were marvellous things for the families as people could get on with doing other things and still be able to hear when the patient needed them.

The Home Support Team needed proper equipment to keep patients comfortable, so it was decided that more specialised equipment was required as the home care got busier. It was agreed that a Meca bed, a Lazy-boy chair and a morphine pump be purchased, which would eliminate the need for injections. They had a bell system gifted by Van Reenan Electrical, and a supply of sheepskins for the patients, plus various kitchen appliances. The co-ordinators were authorised, following professional advice, to obtain professional nursing help for extreme cases.

There was an active group of volunteers in 1989 and the store of equipment continued to increase. Marie Clarke was ably co-ordinating the HHST volunteers. After two years in the job as secretary, Jan Cook relinquished her role as secretary with Liz Connell taking the position over from her.

"My role as secretary included fundraising, taking minutes, writing thank you letters to people who donated money and at times involved public relations too. I had an old typewriter and kept carbon copies of everything for the files. I enjoyed the role and felt that I was doing something worthwhile, working towards helping others. It was fulfilling and fun. The families were so grateful and the community very supportive. I did all my work from home, but we met in each other's homes for committee meetings. The workload was quite big, and we had no computers back then. We would phone around to let everyone know where the meetings were going to be held. We didn't have much in the way of outgoings apart from paper, postage and the odd bits and pieces. We would buy our own paper and donate it. Newsletters were either posted, dropped in letterboxes or sometimes, Trixie would deliver them on her bicycle. We all built wonderful friendships."

Liz Connell

Taupo Hospice continued to grow and consolidate. Membership increased and assistance in various forms as well as generous donations from a wide range of individuals, clubs, organisations and businesses was received. There was good support too from the local media.

By 1990 a lot more of the terminally ill patients were being looked after in their own homes by friends and relatives who had great confidence in the hospice volunteers and their support. There were around 20 volunteers at this time. It was decided that two of them would support each family, so that if one happened to be unavailable, the other support volunteer would already be familiar to the family and patient. The two co-ordinators, Marie Clarke and Virginia Nelson, were responsible for all the administration for Hospice Home Support Team (HHST), matching suitable volunteers with patients' needs, organising drivers for trips to hospitals in Hamilton and Rotorua, and liaising with the District Nurses.

The biggest fund raiser of 1990 was the Huka Lodge Fashion Show held in May. Huka Lodge provided the wine and food, waiters and the venue and Flirts Fashions gave a preview of their autumn and winter fashions. Money raised from this event enabled the purchase of Spenco mattresses, chairs, chair covers and boots to relieve pressure areas in bedridden patients. Another morphine pump was bought, plus books, videos and audio tapes for educational purposes.



Helen Clelland of Flirts Fashions, with Merrill Ridley and Alex van Heeren, owner of Huka Lodge

## Memories of a Home Support Team member

I had had a lot of experience with terminal illness with friends and family, and I felt productive being able to help them. I thought that to enable me to do this properly, maybe I could join Hospice and get some training. I was the youngest by a long way at the age of 37. I started volunteering with the Home Support Team at hospice in 1989. I'd had a year's training previously at the REAP Centre. A psychologist and sociologist offered us listening skills. We were all volunteers who were affiliated with or going to join a social service, and all went for basic listening skills. I just loved it.

In those days you were generally asked to have one hospice friend at a time. I say 'friend' because we were not qualified enough to call them patients. We were taught firstly that we had to support physical comfort and see if anything was needed. If there was pain, I would contact the co-ordinator who would contact the district nurse or the doctor.

Boo Gunn was wonderful and took me under her wing and I remember her taking me to her house to learn to bed bath a large doll. I was given a cake of soap, a dish and a plastic bowl with warm water in it. Instead of putting the cake of soap back onto the soap dish, I dropped it into the water, a big booboo. Through WWII years you couldn't waste soap by putting it in the water and I got pulled up. After I'd had my lesson, I went to my friend who was 90 and said, "I have just been practising on a doll, can I practise on you now?" He looked at me and smiled and said, "No way."

We would often be assigned somebody in teams, especially if day and night, and I would be assigned with another volunteer who was a nurse, Alise Braider. Sometimes the patient was fully cared for, so you became the friend to the caregiver. I didn't mind where the role was. If the daughter was minding her dad and he didn't need support, I would be her support. You fitted where you were needed.

I had a lovely 'friend', a psychiatrist, and his wife needed someone to sit with him while she had a break. I remember him asking me, "Is there anything I can help you with?" I replied, "Well actually you could help me. You could help me to be a really good Hospice volunteer." He said, "Alright. Firstly, never pretend to be any more than you are. Now what are you? Are you a nurse? No. Are you a trained counsellor? No. What can you offer?" I said, "I can be a good friend." He said, "That is enough." So, I asked if he could give me some tips on communicating and he taught me so much.

The group I was in had ongoing training at least once a month, sometimes in Rotorua. The training could be on bereavement, or on how young children treat the grief of the death of a family member and how they process it. I became an avid follower of Elizabeth Kubler Ross. A lot of it is understanding yourself. We would have courses on our fears or our prejudices and had to sort through those feelings to be able to support somebody else.

Sometimes, if appropriate, I would take the girls with me to the hospital, especially if it was a grandad. They would go in and give the friend a hug and give them a small gift, perhaps something that they would like to eat. They would all chat and it would lift his spirits.

Often when a patient was having medical treatment, they would look for alternative therapy. To stay within the boundaries of Taupo Hospice criteria, Marie Clarke told me that I could do anything to support one of my friends as long as the alternative therapy did not cause them to give up orthodox medicine, did not hurt them in any way, and also the therapy was not to cost them exorbitantly.

We were not supported with petrol costs or any cost at all at that time. If the person needed food, we would do some baking ourselves. We would often cook meals and it could be a specialised diet so it might be casseroles, soups, sago or rice puddings.

I really enjoyed going up to the hospital in the evenings. I would sit with patients and hold their hand or be there with the family if needed. I would ask my husband to make cocktails and then take the cocktails up to the hospital with a straw and tell the nurses at the nurse station what I was going to do. I remember freezing whisky in cubes and put it in little muslin bags. I would take up the crushed whisky in a container, put some into the muslin and tie string around the end so it was like a cherry. When my Scottish psychiatrist friend was lying in hospital, the nurses were offering him jelly but he had no appetite for it. He was lying with his eyes closed and I asked him if he felt like a whisky. Well his eyes shot open, so I rushed home, got the crushed whisky and went back up. I popped it in his mouth, and he sucked it for all it was worth. I held the end of the muslin so he wouldn't choke, and he just loved it. That was the greatest pleasure for me.

I had so many memorable times. I remember a friend I was with for 18 months. She had breast cancer and bone secondaries. I remember her lying on her bed with me beside her. She was great on meditation and loved to do these creative visualisations. I was lying there, and she said, "I am ready to go. Shall we do a meditation?" I said, "Alright." I was to talk her through it. I knew what she wanted because we had discussed it and done it many times. "Are you alright? You are going to let go soon." "Yes."

"You are in this lovely garden. You are walking through this garden and in the distance, there is a fence. There is a gate. Your loved ones are behind the gate and you can see them in the distance. Now you are getting closer, you are going to open the gate and you are going to go through. You are going to be with them, and it is all going to be alright." I lay there waiting. The next thing she opened her eyes, looked at me, and said, "Damn I am still here!" Then we had a good laugh. It was about two weeks later that she died. To have a time when you could lie on a bed with someone and share moments like that were very precious.

I remember baking Arthur a birthday cake with ninety candles. He had a lot of hair and Marie Clarke, who had come down for the celebrations, had to rush in and hold his hair back when he leaned in to blow them out or he would have set himself alight!

I would ring Marie every afternoon and report on my interactions with all my Hospice friends during the day. To me it was a comfort as I had no one else I could talk to as it was confidential, and she was always available for me. I would tell her about my day, and she would check to see if I was alright. She attended every funeral with me, and with all the other volunteers. It was hugely time consuming. She had her own patients to see too. All our meetings were held at her house and often some of our workshops were held there too. We had a meeting once a month and would go around the group to see how they were all managing and if there were any problems. To share with the group and ask for practical assistance like meals was great. Sometimes we had a friend who needed meals every night so we could ask for volunteers in the group to do some baking or meals, or we might need help with the equipment.

We were also taught how far you could go with personal contact. Marie taught me that when you meet someone new in their home, you didn't sit and talk to them and expect them to open up, you found something you could do for them or with them and you found that, side by side they told you things that they needed to say and didn't want to tell their family because it might be too painful. Often, we would go for a drive and visit a café or gallery. Driving in the car was also a place they would like to talk.

You fitted in with whatever the family or person required. Just as a good friend would. Knowing that someone was there to help them was wonderful. Marie used to say "don't fill the space with chatter. No talk at all is often fine. When a person is really ill, they don't want you talking constantly. It is exhausting, so just sit there with them, be there or hold their hand. Sometimes being quiet is what people want."

Awareness of hospice was by word of mouth in those days and families told their neighbours and their friends. The district nurses were good at promoting the service. The doctors were wary that volunteers with no medical training were going into people's homes, so they needed to feel confident that the volunteers were responsible in their support and had some training. There were a lot of volunteers in the home support team and the volunteer co-ordinator made sure each of us could cope with the care giving, emotionally and physically, and we had the support we needed. The district nurses also gave us ideas we could use to support the patients from a nurse's point of view.

When Virginia Nelson resigned and Nancy Williams became co-ordinator, I felt the timing was right for me to leave. I had volunteered for just over five years. I do miss having the personal contact though.

Later, I used to go to Sunset Street on Thursdays to take art classes with Suzie Kuper. Hospice supplied the pottery and I would take up plaster moulds. We also made flowers. There would a lot of us sitting at a long table and sometimes there would be carers and patients. All I had to do was co-ordinate it and I loved it. The atmosphere at Sunset Street was always welcoming. Suzie did the firing of the clay. It was a wonderful outlet for patients. We used to laugh so much and have so much fun! The patients would tell funny stories about their lives while we were working with the clay and there was always lots of laughter.

Judi Smith

#### The Nineties

More referrals were coming in as the Taupo Hospice services became better known in the community. Very generous donations and bequests assisted with the purchasing of equipment and providing the home help services. The Hospice movement was growing in New Zealand and the Friends now had over 100 members. Community awareness of hospice continued with events, displays in the Taupo Library, newspaper and radio interviews, all of which encouraged new members to join.

For a number of years, Tegel Chicken and Pak 'n Save had donated a proportion of Tegel product sales to the Taupo Hospice for equipment and the training of volunteers. Trevor Jones was extremely generous in his support of the hospice. One year, Trixie Tindall dressed in a chicken suit for the promotion which created great interest.



Trevor Jones, the owner of Pak 'n Save handing a cheque for \$1200 to Joan Stewart and a chicken named Trixie

"Trevor Jones was amazing, and you could always go to him if you needed anything. I thought I would be incognito wearing the chicken outfit to Pak 'n Save but while walking down one of the aisles this little flying figure suddenly came across shouting, "There's my Nana under those chicken feathers." Then the whole shop knew it was me!"

Trixie Tindall

Volunteers and families found the high-quality equipment invaluable in caring for their patients. Electric beds, wheelchairs, oxygen regulators and mattresses were purchased and stored in a private home in Bonshaw Park. The Spenco mattresses were well used and were laundered regularly at Perma Clean. Some excellent new books and videos were added to the library.





Samples of some of the equipment purchased and stored at Bonshaw Park

Up until this stage the co-ordinator had not been reimbursed, but the Taupo Community Hospice Trust (TCHT) agreed to partly reimburse her for petrol expenses, mileage allowance at 41 cents per kilometre and pay the telephone rental. Volunteers using their own cars for visiting patients could be reimbursed. Regular social gatherings and annual "thank you" functions were well attended and enjoyed by volunteers and their partners.

Ongoing training for Hospice Home Support Team (HHST) volunteers continued in communication and listening skills, grief and bereavement. In November 1993, ten volunteers had a day trip to Cranford Hospice in Hastings to see how a residential hospice operated. The Friends paid the cost for a District Nurse to attend a Stomal Therapy course and for members to attend the Hospice NZ Annual Conference and various co-ordinators' seminars, in order to keep in touch with the latest developments and the wider hospice movement.

To a frequently asked question, "How many patients do you have?" the co-ordinator for HHST in 1993, Virginia Nelson, responded. "This is impossible to answer. We care for a few people for a number of years, some for a few days, at times there may be three or four patients, at other times many more and the time input varies tremendously." As of January 1993, the HHST had cared for and supported 31 families.

Needs changed all the time and some of the help provided included arranging and costing funerals, information from Social Welfare, collecting prescriptions, shopping, laundry, special meals, letters, reading and hours visiting at the hospital, plus fulfilling some of the emotional needs of the patients too. There were patients from a variety of backgrounds and on one occasion, on advice, a patient was turned down because where he lived would have necessitated a police escort to visit. The volunteers ably coped in a range of situations.

In May 1993, the Friends met with the Trust to discuss the possibility of finding, and either renting or buying a suitable place to store equipment and to use as a meeting place. The Trust were enthusiastic. It was agreed that they did not want a building with a lot of maintenance, nor did they wish to eat into their funds. By August, a storage building, owned by Strettons, behind the BNZ had been found for a reasonable rent. Its central location was convenient for both the volunteers and the District Nurses. Hospice had by then purchased three electronic beds, a gas lift chair bed and, with the other equipment, the secure premises and insurance was vital.

Both Patricia Morrison and Gordon Melville resigned from the Trust that year and Pat Bradley was appointed to the Trust Board.

Jenny Thomas, a physiotherapist who specialised in the treatment of lymphoedema, which often affected the terminally ill, gave a lecture and a workshop was held at the Taupo Hospital for physiotherapists, nurses and District Nurses. The Taupo Community Hospice Trust sponsored this educational weekend. An annual "thank you" event was held for the volunteers to acknowledge their dedication and all their hard work.

The Friends had an excellent relationship with the Taupo hospital, and the dedicated volunteers who worked alongside family doctors, district nurses and other professionals, to ensure that terminally ill patients could be cared for in their own homes. New rooms at the Taupo Hospital were available for Hospice patients in circumstances where the patient could not be looked after at home. Fundraising, administration and volunteer co-ordination was still being run out of private homes. Nancy Williams had taken on the role as co-ordinator in 1994. An enquiry was made to Hospice NZ regarding Liability Insurance for volunteers.

In August 1993, a letter was written to Marion Cooper of Te Omanga Hospice asking for permission to replicate their successful idea of a Memorial Christmas Tree, both to raise funds for the TCHT and to remember loved ones who had passed on. With permission granted, the search was on for a suitable spot in town for it to be housed. After some discussion with the Council it was decided to place it in the Taupo Library.

This was the start of the "Light up a Life" campaign, which became a regular Christmas appeal, and which is still in existence today.



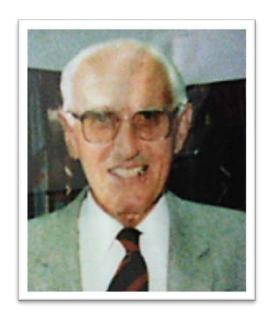
Joy Kiddle, Trixie Tindall and Liz Connell decorating candles "the glitter was everywhere, but it was fun."

People were encouraged to buy a paper Memorial Candle for someone who could not be with them at Christmas, write the name of someone special on the back, and to pin their candle either on the Memorial Tree in the Taupo Library which Library staff decorated beautifully, or their own tree. Six hundred candles were printed and decorated by the committee. These paper candles were sold at a stall in Horomatangi Street manned by two volunteers and in the Taupo Library. Vita Health Foods stored the table and chairs each night. The campaign proved to be very successful and was given considerable community support.

"We spent an enormous amount of time creating the candles for the "Light up a Life" campaign each year. There was glitter everywhere for a long time, but it was fun. We would have a little Christmas tree on the table and then after the day selling candles, I would go down to the Library and hang them on the tree. It was a great idea and struck a chord with a lot of people."

Liz Connell

In 1994, Taupo Community Hospice lost two of its founding members. Boo Gunn resigned from the Friends committee after years of giving invaluable service and was elected a life member of the Friends, and Gordon Melville, who had been instrumental in obtaining initial funding for Taupo Hospice, passed away.



#### Gordon Melville

Gordon and his wife Marjorie emigrated from England to Taupo in 1969, where he quickly become involved with many local voluntary and welfare agencies in the town. He was known as a man who gave one hundred percent to anything he undertook.

In 1982 he obtained funding for a group of five people to attend Gisborne Palliative Care Conference. This event became the inspiration which launched the Taupo Community Hospice Trust with Gordon being elected its first secretary/treasurer. In 1986 he became the first Chairperson of the newly formed Taupo Friends of the Hospice Society. A man of great ability and dedication, Gordon was involved in all aspects of the Hospice from finance and funding to ensuring that volunteers attended the courses necessary for them to carry out their work in the community.

Gordon stepped down as Chairman of the Taupo Friends of the Hospice in 1988 and received a Community Volunteer Service medal for his involvement in welfare groups from the Governor General in 1991. He died on the 5<sup>th</sup> of January 1994 and a plaque was commissioned in his honour by the Taupo Hospice.

During November, an evening was arranged at the Women's Club to which all the local doctors, Taupo Hospital doctors, District Nurses from Taupo and Turangi, and volunteers were invited. Members of the Turangi community showed an interest in becoming involved with Taupo Hospice in their area.

1995 was a busy year with two successful fund-raising campaigns, the street stall and the "Light up a Life" candle campaign. One thousand, five hundred candles were ordered that year. Nine volunteers attended a "Good Grief" seminar and two volunteers attended the Hospice Conference in Dunedin. New members were welcomed, and subscriptions remained at \$5.

All Hospice equipment was marked "Taupo Hospice" and the equipment cleaned and checked twice monthly. Records were updated with all the new equipment and an updated list of all available books, videos and audio tapes was compiled. All equipment removed from the storeroom was to be signed for and witnessed as more people had access to the storeroom and equipment was also taken to Turangi.

In August, a concert by the Barbarians, a group of Australian medical practitioners and Dr Peter Fleischl of Taupo, was held at the Taupo Museum. The function was a great success and the Trust was a part-recipient of the proceeds.

In 1996, Merril Ridley retired at chairperson of the Friends and Dr Adrian Webb as chairman of the Trust. Between them they had shared 20 years with Hospice.

"The commitment of volunteers initially was amazing and still is. We fundraised to purchase equipment and helped patients and families in their own homes. Hospice was able to give them so much care and support. People could not believe there was so much help available because they felt so alone at the start. Lake Taupo Hospice has developed beyond our wildest dreams. It is so amazing. I am very fortunate and blessed to have been able to see our dream grow and develop."

Merril Ridley

Marie Clarke became a new member of the Trust, Joan Stewart took up the reins as the chairperson of the Friends and Liz Foley, the role of co-ordinator for the support team. Liz compiled a pamphlet on the volunteers' job description and organised a two-day seminar run by Katherine Gibson to cover listening skills and communication. All volunteers were obliged to attend ongoing training sessions to give them the necessary skills to carry out their demanding role.

"We moved to Taupo in 1993. I heard about the Taupo Hospice then and thought I would like to get involved as I already had had a bit of experience with it. Way back, my daughter was involved with the Duke of Edinburg programme in Wellington. Mary Potter had just opened and Bridget, at 13 years old, decided to volunteer there as part of the programme's requirements. I suggested to Sister Margaret that I do the volunteer co-ordinator programme too. Working with Sister Margaret and the patients persuaded me to further my nursing as a mature student.

Before I could blink, I became the Volunteer Co-ordinator for Taupo Hospice. When I first started, a couple of boxes were handed over to me by Nancy and we had around a dozen or so volunteers. Our volunteers were busy going into homes to care for people, making meals, shopping, etc. The District Nurse used to contact me and tell us who needed to be visited. Referrals mainly came through the nurses."

Liz Giesen (Foley)

Over the years, several dedicated volunteers came and went, all having experienced wonderful friendship and support, and all having felt that they gained so much more than they gave. They received inspiration from their patients and with one particular quote:

And the courageous patient who said, after extensive surgery for bowel cancer: "Better a semi-colon than a full-stop!"

The storage equipment room was becoming too small as a lot of the District Nurses' gear was stored there and it was difficult to keep track of equipment. As well as the larger equipment there was a supply of wool underlays, over bed tables, sheepskin knee and elbow pad protectors, etc. Four electric beds were kept at the Hospital and the District Nurses organised the Hospital orderlies to transport the beds and set them up in the patient's home when needed.

The Hospice Trust suggested that money continue to be raised to reach a target of \$100,000 as a foundation to work from. An increasing number of people were requesting donations to Hospice in lieu of flowers and the ongoing support from individuals and community groups was enormously heart-warming.

Fund raising events such as the coffee morning with a raffle and food demonstration by Jill McIsaac, were a successful way of boosting the coffers and having fun. The committee members as ever, were cheerfully supportive in various ways, this time being asked to "bring a plate of whatever!"



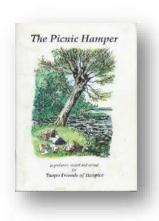
Sharing a toast after a successful fundraising wine auction are from left: Liz Connell, Joan Stewart and Managing Director of Grantley's, Ron Horsley

Education for volunteers continued and in November 1996 they attended an Aids workshop at the Tauhara Centre.

The annual contribution to Hospice NZ was increased to \$500 which Taupo Community Hospice was not happy about. They were a small hospice, did not have palliative care and felt that the increase was not justified. A part payment was paid that year.

In 1997, the Friends received a donation from the Jack and Emma Griffin Charitable Trust to purchase specified equipment. A display of the new equipment purchased with the donations received from the Charitable Trust, Paekeke Lions and the Inter-Church Welfare Society was held at the St John's Ambulance rooms. A 'patient turner' was amongst the new equipment purchased. The District Nurses were extremely grateful for the provision of the most up to date equipment which made it much easier for a patient to be cared for in their own home. The volunteers were an invaluable asset in assisting the nurses in supporting the patients and their families in extremely stressful times. It gave the families confidence and security that their loved ones were comfortable and professionally managed.

Membership had increased and there were now 171 members of the Friends. Olivia Marchant stepped into the co-ordinator's role of the Hospice Home Support Team and Liz Connell resigned as secretary of the Friends after eight years' service. Paul Burdett resigned from the Trust and was replaced by Michele Roddan.



It was suggested that a fund-raising recipe book be created with favourite recipes from members and well-known locals. Joan Stewart suggested picnic favourites. There was some resistance to the idea of yet another cookbook, but Joan and Margaret Shaw were determined and presented the committee with a delightful book of recipes and charming "Wind in the Willow" characters. One thousand copies of *The Picnic Hamper* were initially printed and sold at \$6 each. These sold out and a further 500 were ordered.

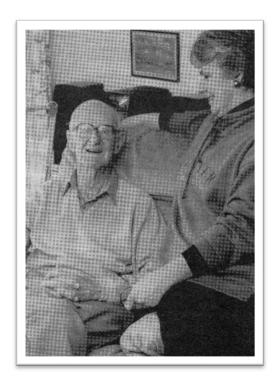
In 1998, Rose Corkin was secretary of the Friends committee and Peggy Donaldson had taken on the role of co-ordinator. Alternative therapies such as massages for patients were explored and applying for grants to cover equipment costs was investigated. Other hospices were offering different services such as 'Stepping Stones', a Hibiscus Coast Hospice social support programme, which assisted the recently bereaved to mourn at their own pace, and with support and a caring environment, move back into family and community life. The Te Omanga and St Joseph's Hospice offered a biography service for those who wished to tell their stories, and have it recorded to share with whomever they chose.

Jim Ridley, who was a committed Trustee of the Taupo Community Hospice Trust passed away in November 1998 and Dr Adrian Webb in 1999. Very sadly Joan Stewart unexpectedly died in 1999 too. She had been a wonderful Chairperson who gently but firmly kept the committee informed, involved and together. Liz Foley stepped in as Chairperson.

To commemorate the death of Joan Stewart and Joy Kiddle, both long-standing committee members and dedicated to the work of Hospice, two trees were planted in the Memorial Walk at the Botanical Gardens: a dogwood for Joan and a camellia for Joy.

Towards the end of 1999, the Friends were involved in helping at the refreshment stations for the Half Marathon, or "Tin Man" event as it was called. Two thousand dollars was received from the organisers, being half the proceeds of the event. Once again, the Christmas Candle "Light up a Life" campaign was hugely successful.





Adrian Webb and Merrill Ridley

#### Dr Adrian Webb

After completing his studies at Wanganui Collegiate, Adrian Webb trained as a doctor, but developed tuberculosis shortly after graduating in 1939. As a result, he was hospitalised for over a year at the Pukeora Sanitorium in Hawkes Bay. This experience had a lifelong impact on his attitude towards patient care and support.

Dr Webb gained vast experience as a physician around New Zealand and Malaysia. His years as a tuberculosis specialist, including time spent in sanitoriums as both doctor and patient, emphasised to him the importance of family and personal attention. One South Island sanitorium where he was stationed, was so isolated that the relatives pitched tents in the grounds to be near dying family members.

From 1978 to 1985 he was Visiting Physician at Taupo Hospital and became the first Chairperson of the Taupo Community Hospice Trust in 1986. He was made Life Member of the Hospice Trust in recognition of his contribution to all his considerable work for the hospice where he was respected and loved by all.

Dr Adrian Webb passed away on the 6th of March 1999.

## **Evolution**

The year 2000, with Liz Giesen (Foley) as Chairperson and Peg Donaldson as coordinator, saw a change of members within both the Friends and the Trust.

An extract taken from the Chairperson's report presented at the 14<sup>th</sup> AGM of Taupo Friends of Hospice on 28<sup>th</sup> June 2000:

"There are 10 objectives which the Society names Taupo Friends of Hospice Incorporated must abide by. The two main objectives are:

- 1. To do whatever may be necessary to assist those people of any age who are terminally ill, and their families, and who are in need of physical and emotional support irrespective of race, creed or religious belief.
- 2. To support and assist whether financially or otherwise any proposal or scheme for the advancement or education of any person or organisation in Hospice care or administration.

To meet these objectives, we must support our volunteers, as it is this dedicated group of women who carry out the main work of Hospice providing assistance to terminally ill patients and their families in various ways, practically and emotionally. To equip our volunteers to meet these needs they are trained in a range of skills including communication and listening. As the fundraising arm of Hospice, we must use our funds not only for providing the essential equipment but also to provide the best possible training and education for our volunteers.

Essential back up support for our volunteer co-ordinator is our District Nurse, Judy Tunnicliffe. One of Judy's greatest assets relating to Hospice is that she has a special interest in Palliative Care. The word Palliative means to alleviate without curing which obviously applies to the terminally ill. Palliative Care or Treatment is synonymous with Hospice Care. It involves the total care of the patient, controlling pain and other symptoms, and also giving psychological, social and spiritual care. At the moment we have available in NZ a Certificate in Hospice/Palliative Care. To achieve this certificate students, mostly nurses, must complete four modules at a cost of around \$450 per module. The modules are designed by the Hospice NZ Education Programme. Judy has completed one module towards the certificate, and I know she would like to complete the other modules when she can fit it into her already busy schedule. Here in Taupo we do not have any health professional with a Palliative Care qualification, so it is important the Friends of Hospice support Judy and any other health professional who wishes to gain this qualification with the guarantee they will remain in Taupo. "

Judy Tunnicliffe gratefully accepted the offer of support which enabled her to attend the Palliative Care Modules offered by the Hospices of Auckland. She said, "Completing these modules will further enhance my caring strategies within the hospice organisation, District Nursing and especially for our current and future patients." Judy commented that the District Nurses were extremely fortunate to have such a cohesive working relationship with the Friends, and they valued the volunteers' support and assistance.

A substantial donation was gifted to the Friends from the Jack and Ena Seagar Foundation in April 2000, which was transferred to the Taupo Community Hospice Trust to invest.

#### Night to Remember Fundraisers



Liz and Tony Gieson preparing for A Night to Remember

The idea behind this Hospice NZ national fundraiser, was to invite friends and family to a special dinner, charge them for the evening and the money would be given to the Hospice Society. The hosts would provide a dinner for six at \$30 per head – 3:1 split of profits with Hospice NZ. Jo Seagar, the Hospice NZ Ambassador, was the inspiration for this project. "A Night to Remember" was significant because it conveyed the prospect of a fun-filled evening and provided an opportunity to honour the lives and memories of family and friends who had died. In May 2000 fifteen Taupo hosts opened their homes for the dinner parties. Taupo Hospice raised \$5,075 from "A Night to Remember", 75% of which was retained, and 25% went to Hospice NZ.

Money raised helped to buy special beds for Taupo Hospice. This successful fundraiser became an annual event.

A trip to the Waipuna Hospice was organised for the volunteers. Katherine Gibson held another workshop and Larraine Lash came to speak to the volunteers.

By now the equipment storage room was proving to be a problem as there was a lack of lighting and no facility to wash equipment. It was very dusty and not easy to keep things in an organised manner. A storage facility about the size of a double garage was put onto the wish list.

**2001 - Year of the Volunteer.** Hospice NZ believed that the voluntary work provided for Hospice constituted the largest of any voluntary group in the health sector. Volunteers of Taupo Community Hospice Trust participated in all aspects of Hospice work from Board Governance to assist patients in their homes, through to the fundraising committee and all the others who gave of their time.

Over the year Taupo Hospice organised a variety of activities to raise funds and promote their service. These included "Light up a Life", the Acacia Bay Fair, the Queen's Birthday Weekend Craft Fair, "A Night to Remember" and perpetual calendars were printed and sold at \$8 each. That year not only did people host dinners for "A Night to Remember", but had a variety of functions including afternoon teas, luncheons and cocktail parties, raising approximately \$7,600.

Training for volunteers was ongoing and in March 2001 a special workshop was held at the Tauhara Centre. The course was conducted by Dr Libby Smales, an internationally recognised Palliative Care Physician with a particular interest in linguistics, communication skills and human relationships, and Dr Hetty Rodenburg, a Neuro Linguistic Programming practitioner whose area of expertise was grief counselling. The 23 volunteers who attended these sessions increased their knowledge and skills considerably. It also gave the eight new



volunteers valuable insight and skills before they were sent out into peoples' homes. Dr Libby and Dr Hetty (seen enjoying the gardens of the Tauhara Centre with a friend) were wonderful communicators and their training proved extremely worthwhile and interesting for everyone attending.

Volunteers also attended training sessions at Taupo Hospital and had physiotherapy training. In addition, 13 volunteers attended workshop training in Auckland, 15 volunteers went to a training session at the Funeral Home and 8 volunteers attended training at Waipuna Hospice. Sadly, Nancy Williams, a wonderful volunteer for many years, passed away in December 2001. She was a great stalwart of Hospice.

Liz Giesen said, "Nancy was a great worker being involved in various community groups. I can still recall the hair-raising ride in her M.G. sportscar, while she smoked furiously, on the way to be introduced to my first patient. She was a wonderful character and we will miss her."

The sale of notelets, calendars and a reprint of 500 of the "Picnic Hamper" recipe book, combined with generous donations and bequests continued to boost Hospice income. Secretary Rose Corkin was kept busy writing thank you letters to supporters who had organised and attended a wide range of events from Mahjong and Bridge afternoons to a nine-hole golf tournament. One thousand candles had been printed for the annual Christmas "Light up a Life."



Life Members of Taupo Friends of Hospice, Pat and Peggy at the 2002 AGM

Liz Giesen resigned at Chairperson of Taupo Friends of Hospice in 2002 and Peg Donaldson stepped down as Volunteer Co-ordinator after 21 years involvement with Taupo Hospice. She and Pat Bradley were made Life Members. Rose Price took over the role of Volunteer Co-ordinator and David Maling accepted a position as representative of Taupo Friends of Hospice.

With the continued growth of Taupo Hospice, there was an increase in budget requirements which necessitated

the need to look outside the normal local fund-raising ventures to help balance the books. The Friends began to submit grant applications to help cover costs.

There were now 39 volunteers in the Home Support Team, five of whom lived in Turangi. Many varied training sessions were held throughout the year. There were also four specialist volunteers who assisted with podiatry, hair and wig care, massage and bereavement support. The team had monthly meetings with guest speakers which were aimed at enabling the volunteers to provide a high-quality service of support care to the patients and their families.

Some of the educational courses offered were:

- Listening skills
- Cultural awareness
- Spirituality
- Practical e.g. lifting, moving, equipment
- Stress and self-care
- Patient needs
- Relationships and family dynamics
- Grief, bereavement and loss

- Confidentiality and privacy
- Legal issues and volunteer role boundaries
- Safety
- Approaching death, practical nursing to help families cope
- Patient needs /whanau
- Alternative therapy

Hospital volunteers delivered edible presents made by the Friends to the families of patients and the families bereaved during the year, delivered by their Hospice volunteers. The home support also had a counsellor to assist them, Iris Alden, who took the volunteers through the NZ Hospice Education course on self-care and coping with stress.

# **Hospice Education Programmes**

"In the early 1980's I completed my nursing through the old hospital-based training in Palmerston North and worked in maternity health for a few years. From there I worked in general practice and did some private contract work for midcentral DHB, running a Women's Health Clinic in the community. I then moved into a newly established role with the Manawatu Independent Practitioners' Association and helped set up and deliver a primary health care service in Feilding to support general practice and work alongside people with long-term conditions who had difficulty accessing general practice. When we moved to Taupo, I worked at Wharerangi Resthome, then at the Primary Health Organisation where I was the Practice Nurse Liaison and Primary Nurse Leader, funded by the local DHB. I was there for five years before I joined Lake Taupo Hospice. During that time, I was studying for my Masters, and I was in one of my Massey lectures when David Maling phoned me and offered me the position.

In May 2000, Janet Gainsford and I commenced our new roles in Hospice, Janet the Nursing Coordinator and me, the Clinical Nurse Educator. There were three components to my role which was to be spread evenly across three days. One day for education in the southern lakes DHB area around Palliative Care externally. One day to facilitate the Liverpool Care Pathways (LCP) – Care of the Dying in the Last Days of Life. The third day was to develop a Carer Programme for family/whānau and carers to enable them with skills to confidently manage and care for their loved ones at home.

Another important part of the role was to develop clinical documents and develop a more ordered approach to policy development. Policies and processes needed to be updated and reviewed, and audits undertaken to identify where our gaps were and the areas we needed to tighten up on. "

Janine Colpman-King

At that time Hospice didn't have a formalised education programme but were doing the best they could with the resources they had. They were delivering Hospice NZ Palliative Care breakfast sessions and whilst employed by the PHO, Janine would attend those sessions. These were held on the first Thursday of every month. Topics changed every month and lectures commences at 7.30 am. It was time to expand the education.

The Liverpool Care Pathways (LCP) was developed in the United Kingdom by the Marie Curie Institute and the objective was to have a formalised process to support non-specialists in palliative care to deliver the best care they could in those last days of someone's life. It was a formalised document aimed at age care facilities, in-patient units at hospices, and another care plan which was community based.

Part of the implementation was to do pre-audits which were then sent to the UK and a data PowerPoint to develop the education packages was sent in return. Once the LCP had been implemented, a post-audit was carried out. The Clinical Nurse Educator would sit down with the district nursing team and work through the audits and any queries the district nurses had. The Clinical Nurse Educator would do the audits in four of the rest homes in Taupo and Hospice as well.

In New Zealand, Liverpool Care Pathways was implemented through the midland region and education packages developed so there was a consistent message being given throughout the area. The midland wide facilitators would meet about three times a year to see how everyone was going, what the challenges were and what was working well. They would meet nationally too, and it was really taken on board in New Zealand with an education package which underpinned it. The GPs found that it was a lot of paperwork and there were barriers. The downfall of the LCP in the United Kingdom was that there was no education given to underpin the implementation. It was not being used the way it was intended and in the United Kingdom there were incentive payments for general practitioners to transfer people onto this pathway, which was perceived as unethical. The LCP programme was withdrawn internationally, and the Last Days of Life Care Plan initiated in New Zealand, which was based on the LCP but also incorporated a cultural and spiritual assessment. Lake Taupo Hospice was instrumental in having that adopted.

The Clinical Nurse Educator/Clinical Quality Co-ordinator (CNE) role was developed in 2012 in response to the growing need for a well-co-ordinated and dedicated education service, along with dedicated clinical quality service improvement activity. From an education perspective the role provided for internal and external specialist hospice and palliative care education facilitating the Hospice NZ Education Packages; HNZ Syringe Driver Training and Fundamentals of Palliative Care, Health Care Assistants Packages and practical skills days, along with organisation of the Genesis Oncology Breakfast and Waikato Grand Round sessions. The CNE further developed hospice and palliative care educational opportunities, and liaised with service providers at local, regional and national levels. From a quality co-ordination perspective the role promoted and maintained clinical quality improvement activities within hospice, planned, co-ordinated and supported the overall clinical quality improvement programme in consultation with the Clinical Manager and aided the promotion, implementation, co-ordination and evaluation of the quality specialist palliative care service provided by Lake Taupo Hospice.

The education role has grown and evolved over the years. A Carer Programme has been developed, which is comprised of six interactive sessions designed to help build the knowledge of people caring for someone in their home. Topics include:

- Hospice and palliative care services and resources.
- The circle of care.
- Home nursing tips.
- Riding the emotional roller coaster.
- Practical/family matters.
- Digital technologies, social media networks and support.

Often when carers initially arrived at Hospice, they felt disempowered. They needed to feel in control and this course equipped and empowered them.

Waikato Palliative Care run project ECHO, which transforms the way education and knowledge is shared by connecting healthcare professionals in the Waikato area, especially those in more remote communities. There is a monthly session which includes 15 minutes of education presented by a topic expert, followed by interactive discussions. Interesting and complex cases are presented so it is a great learning platform as well as peer review.

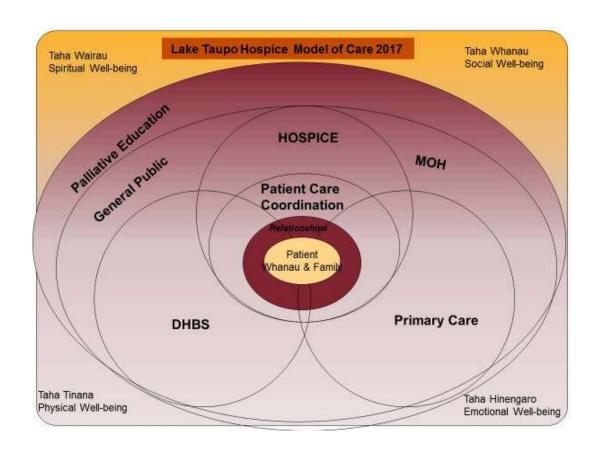
Lake Taupo Hospice runs the Hospice NZ Fundamentals of Palliative Care courses which include:

- Essence of palliative care.
- Ethical issues in palliative care.
- Pain and symptom management.
- Palliative care for people with chronic illness.
- Palliative care for people with dementia.

- Communication skills.
- Last days of life.
- Loss and grief.
- Caring for ourselves.
- Introduction to spiritual care.

Syringe Driver workshops and Palliative Care for Care Assistants are the other education resources available. Sometimes it is difficult to get everyone into one space at the same time, so e-learning is offered on different platforms.

Along with formalised education, Hospice keeps other organisations informed on the services they offer, invites professionals to give talks to staff and volunteers, and organises updates from the Waikato Palliative Care Medical Specialist to which the GP teams, aged residential care teams, nurses and doctors, and the Taupo Hospital nurse practitioners are invited.



## The Restructure

In 2002 there were three organisations involved with hospice work in Taupo. The Friends, who, as well as fundraising, managing and co-ordinating the volunteers and providing and maintaining equipment necessary for Hospice care, were now being called upon to provide informative and professional information on Palliative Care. They also had to report to Lakeland Health, the Ministry of Health and Hospice NZ on the Taupo District. This additional administration was fast outgrowing their limited resources.

Secondly, there was the Taupo Community Hospice Trust, which at this time consisted of Gary Chapman (Chairperson), Pat Bradley, Marie Clark, Merril Ridley and Michelle Roddan. In addition, the Malulani Trust Account had been set up in 2001 with monies received from donations. This Trust funded Dr David Nixon's, a Trustee of this Trust, work in Taupo in Palliative Care. To work out how to manage matters in a more practical way, a meeting was held between the Trust, Dr Nixon and Julie Eilers, Community Liaison Case Manager for Lakeland Health. This resulted in combining the three groups and sharing resources under one organisation.

A suggestion was outlined for the new Trust to comprise six members, possibly to include three Friends, two doctors and one person from the Malulani Trust. Sub-committees would be formed under the headings of Clinical, Administration and Friends. It was thought that by combining these three groups, sharing resources under one organisation, the skills and talents of all would benefit Hospice. Later the Malulani Trust pulled back from making money freely available to Taupo Community Hospice Trust (TCHT) due to their tax requirements, but TCHT could still apply to them on a one-off basis should they have a special project that would require their help. At a meeting of the Friends in February 2002, the chairperson announced that there would be no direct funding to Taupo Hospice from Malulani Trust. The Malulani Trust had decided to separately fund carer relief on a case by case basis through St John's Wood Retirement Village.

There were changes afoot for the Trust too. The future structure of TCHT was about to change, and many issues had been worked through over the course of the previous year. On the 9<sup>th</sup> February 2002, a meeting of the Taupo Community Hospice Trust was held at the Hospital Library, co-ordinated by Dr Jocelyn Tracey from First Health Ltd.

Those present were:

Age Concern: Lyndsay Benefield

First Health Ltd: Ross Smith

Hospice NZ: Ann Martin

Lakes District Health CEO: Cathy Cooney

Lakes District Health Rep: Laurie Burdett

Lakes District Health Rep: Joan Williamson

Lakeland Health TC Hospice: Julie Eilers

Lake Surgery: Liz Fitzmaurice

Taupo Community Hospice: Gary Chapman

Taupo Community Hospice: David Maling

Taupo Friends of Hospice: Liz Foley Giesen

Taupo Friends of Hospice: Rose Corkin

Taupo Friends of Hospice: Merril Ridley

Taupo Health Centre. TC Hospice: Dave Nixon

Taupo Hospice Volunteer Co-ordinator: Peggy Donaldson

Taupo Hospice Volunteer Co-ordinator: Rose Price

Taupo Hospital: Jean Glisson

Taupo Hospital and Health Society: Joan Gardner

Taupo Medical Centre. TC Hospice: Peter Battersby

Tūwharetoa: Danny Loughlin

Tūwharetoa Health Board: Raewyn Bourne

Waikato Hospital: Rob Jaffrey

Waikato Hospital: Des Swanevelder

Gary Chapman explained to the group that Taupo Community Hospice Trust had been the investment vehicle for the Friends of Hospice, which provided equipment and funds, and that these groups now found it necessary to be combined. All the participants at the meeting had been invited to debate issues that would improve the situation of the terminally ill and their families.

Julie Eilers explained that Lakeland Health contracted to provide Palliative Care through the District Nurses, who worked closely with the Hospice Volunteers. Rotorua's Community Hospice held the contract for the Lakes District but had advised the Lake's DHB in July 2001 that they would no longer provide night nursing to Taupo and Turangi. Night nursing cost \$150 per night. In the interim Lakeland Health, the main provider of publicly funded health services in the Rotorua/Taupo area, had agreed to cover the difference of \$70 per night even though they had no budget or contract to do so.

With the objective that people in the Taupo-Turangi area who were terminal have access to quality palliative care, the groups discussed the strengths and weaknesses of the current set up, targeting key areas needing improvement, some of which were:

- Twenty-four hour co-ordination service in line with NZ strategy.
- Training and education for volunteers and others, a co-ordinated approach which included counselling skills.
- Better promotion of services.
- Address night nursing issue and funding.
- Early referral systems.
- Access to specialist, training and advice.
- Improved culturally effective and safe services. Involvement of Iwi.
- Free access to all services.
- Rural areas access and cost.
- Better post-bereavement services.
- Better information on volumes, funding and needs.
- Financial assistance for patient, family and whanau.
- Improved services for children.
- Expansion of role for Aged and Specialist Care providers.

Five groups were formed to discuss the above issues.

It was decided at the 16<sup>th</sup> AGM in June 2002, that the Trust would comprise one member of the Friends Executive Committee, one volunteer, one GP, one Tūwharatoa and one Lakes District Health Board member as representatives on the Trust. Those representatives would have the power to elect two more members. Previously the Trust was only involved with the investment of funds, but it would now take on the administration of the Friends too. A Management Sub-committee of the Trust was elected at the meeting and a promotional group established.

Following on from this meeting, the Annual Meeting of the Trustees of the Taupo Community Hospice Trust was held on the 10<sup>th</sup> October 2002. The following Trustee appointments were made:

Chairman: Gary Chapman

Deputy Chairman: David Maling

Secretary: Edna Walker

Treasurer: Liz Ransom

Taupo General Practitioner's Association: Dr David Nixon

CEO of Lakes District Health Board: Julie Eilers

Taupo Friends of Hospice Inc. Society: David Maling and Jan Wynn-Williams

Tūwharetoa Trust Board: No appointment

Sub-Committees of the Trust were Clinical, Administration and Fundraising. The Administration Committee would submit their management plan for purchase of equipment, and this would be incorporated in the Trust Business Plan. The Tūwharetoa Board representative would assist the Trust in co-ordinating cultural awareness for the Hospice as the Trust recognised the high proportion of Maori population in the Taupo/Turangi area.

### **Determination of Sub Committees of the Trust:**

#### 1. Clinical

The two Trustee appointments for the Clinical Sub Committee were Dr David Nixon and Jan Wynn-Williams. The Committee comprised of:

- Dr Peter Battersby
- Dr Liz Fitzmaurice
- Vera Lamb Secretary
- Jan Wynn-Williams Trustee
- Robin White Volunteer
- Rose Price Co-ordinator
- Janet Gainsford District Nurse

- Dr Meg Gustafson
- Marlene Snowdon Iwi
- Liz Bell St. John's Wood
- Anne O'Rourke St. John's Wood
- Dr David Nixon

### 2. Administration

The three Trustees were Gary Chapman, David Maling and Julie Eilers.

#### Committee Members:

- Gary Chapman
- Tony Chrisp
- Liz Ransom
- Merril Ridley
- Jo Maling

- David Maling
- Jo Tinworth
- Stuart Williams
- Julie Eilers

## 3. Fundraising

The two trustees were David Maling and Howard Wedekind. Committee Members:

- Rose Corkin
- Pip Broad
- Stuart Williams
- Margaret Shaw
- Liz Ransom

- Lynn Cooper
- Robbie Shearer
- David Maling
- Howard Wedekind

A status quo budget was presented for consideration with the Business Plan and it was suggested a cheque account be opened for the Trust at the Westpac Trust Bank. The signatories were any two of the Chairman, Deputy Chairman and Treasurer.

Taupo Hospice changed its name to more clearly reflect the area they covered, incorporating the Turangi and Southern area of the lake.

#### Mission Statement

Taupo Turangi Community Hospice exists to provide care and support to the terminally ill and their families so they may live life fully and as comfortably as possible.

#### Vision Statement

Be recognised for the high standards of care and of quality services for Taupo Turangi Community.

# Key Objectives

- 1. That patients and families are our prime focus.
- 2. Promote integration of providers for the benefit of the terminally ill, their families and whanau.
- 3. Recognise and respect cultural difference.
- 4. Update and develop the palliative care training of providers.
- 5. Educate the community of the benefits of services from Hospice.
- 6. Recruit and retain appropriate personnel.
- 7. Establish fundraising initiatives to support mission statement.
- 8. Ensure the long term financial viability of the Trust.
- 9. To adhere to the guidelines of Hospice New Zealand "Standards for the Provision of Hospice/Palliative Care".
- 10. Aim to ensure patients have access to clinical support 24 hours a day, seven days a week.
- 11. Establish a base with a view to developing services.
- 12. Regularly consult with providers and consumers.

# Te Nohanga Kotahitanga o Tūwharetoa Iwi Health Governance Trust Inc.

In 1995, Kim Gosman was new to her role in the newly formed Tūwharetoa Health Services (THS) implementing and developing services.

Sir Ross Jensen, chairman of the Regional Health Authority, invited Ngāti Tūwharetoa to become involved with service delivery. The Hapū had three major hui to discuss this, the outcome being the first Iwi Strategic Health Plan. They formed a managing committee comprised of eight members, each with their specific roles.

"The instructions were very clear, they (the people) wanted their own trained, their own employed and their own to work with them (the people). We were to develop a Māori work force, prepare service proposals and develop a data base in ten weeks. With a group of others, we submitted the first service proposals that were successful. At that time there was no money for any type of home care available for people who chose to come home to die. It was difficult for Tūwharetoa Health Services (THS).

Nevertheless, THS supported whānau to provide care at home. We were fortunate to have a member of the staff who was a qualified and experienced Enrolled Nurse. She was also trained as a hospice personal care volunteer. Her skills included training whānau who were caring for patients in their own homes. If any special equipment was needed, a phone call often saw a truck arrive with a mattress and equipment, no questions were asked. It was a difficult time."

Kim Gosman

In 2000, under the Health and Disabilities Public Health Act, there was a requirement for the DHBs to have a formal relationship with Iwi/Māori around the country. This was the beginning of the Lakes DHB association with Ngāti Tūwharetoa.

Kim had extensive experience and connections in Māori health, women and children's health, and rural health. She was committed to advancing access to timely, quality palliative care services for families and whānau in rural areas, especially Mangakino and Turangi. Kim connected back with Lake Taupo Hospice again in 2005 when she met Suzie Kuper, the Palliative Care Co-ordinator. Suzie was able to share all the services which were available for palliative care and Lake Taupo Hospice and THS developed an amazing relationship. "Suzie was indeed an Angel . . . ." David had earlier approached Kim to join the LTH Trust and she was keen to do so.

Te Nohanga Kotahitanga o Tūwharetoa (TNKOTH) is a hapū based iwi governance body. The core focus of the Trust is to improve health outcomes for Iwi Maori within the Tūwharetoa rohe (area). This focus exists because of concerns about inequalities in health and the ineffectiveness of current health structures, services and outcomes.

To facilitate achievement of the focus the Trustees (TNKOTH) signed a Memorandum of Understanding with the Lakes District Health Board in June 2002 on behalf of the Iwi. THS services were for "all who live within the rohe o Ngāti Tūwharetoa. Kim was told that we in Tūwharetoa share our gifts . . ." (Sir Hepi Te Heuheu 1994)

The (TNKOTH) Trust Membership is made up of three health representatives from each of the five health regions of Ngāti Tūwharetoa, which are:

- Te Runanga o Tutetawha Ki Taumaranui, Taumaranui
- Te Mataapuna, Turangi
- Te Hikuwai, Taupō
- Kit Te Tonga, Tokorangi, Bulls, Taihape
- Tūwharetoa Ki Kawerau, Kawerau

A total of 15 members. An additional three Trustees were officers of the Charitable Incorporated Trust. Ratana Wall was the Chairperson with Emily Rameka and Gail Ngatai. TNKOTH was supported by Kaumātua, Tuatea Smallman, Arana Taumata and Ned Wikaira.

Ratana Wall had been involved with Lake Taupo Hospice (LTH) for quite some time. In 2002 when TNKOTH was formed, a Memorandum of Understanding (MOU) between the Lakes DHB and Ngāti Tūwharetoa in which Ratana Wall was involved, was signed. Ratana sat on one of the three regulatory Statutory Committees required, the Hospital Advisory Committee (HAC). Two other members were representatives on the Community and Public Health Committee (CPHAC) and the Disability Support Services Committee (DSS). They would attend the board meetings and would then notify the Tūwharetoa sector of grievances and disparities with regards to Māori health, and all that had been discussed at the meetings.

From 2005, LTH became the recognised provider of specialist palliative care for Māori in our area. The mandate was granted to us by Ratana Wall and Te Nohanga Kotahitanga – the Tūwharetoa Iwi Health Governance Board. This mandate continued under the direction of the succeeding Kaumatua Ned Wikaira, and Kuia, Peehi Wall, Ratana's wife.

Ratana was the Kaumātua on the TNKOTH and LTH boards. He was a visionary, a very well-respected humble man and a person of wisdom and reason. He wanted to be more effective for Māori. Initially very few Māori knew about Hospice and thought it was only for Europeans. It was a whole new concept for people, and they didn't really know how Hospice operated or what services were offered.

Ratana would report back to the Māori elders following board meetings, hapū were informed through iwi meetings, and then the information was taken to marae around the area and back into the community. The objective was to decipher what was relevant to Māori as a whole and how to put it into terminology so they would understand it all.

Hospice was always Ratana and Peehi Wall's passion. Later, he seconded Puti, his daughter, to join the LTH Trust too. She attended board meetings, which was a great experience for her, and would report the most important things back to the TNKOTH meetings. Ratana became the face of Ngāti Tūwharetoa in relation to Hospice. He was the quiet one and Peehi, the vocal one. It was during their years that a strong partnership was formed between Lake Taupo Hospice and Ngāti Tūwharetoa.

Ratana was a great support for Suzie Kuper, the Clinical Manager, and it was an education both ways for them. She sought his advice when developing new pamphlets. Ratana's photo was on the pamphlet which gave Lake Taupo Hospice credit in the eyes of Māori, as he was held in high regard. There was curiosity about why Ratana was involved with the organisation and if he endorsed the philosophy, then it must be okay.

Kim related a lovely story from one of the THS workers. "Beryl went to see her aunty when her children had gone off to school. She popped in and her aunty offered her a cup of tea. Beryl went to the cupboard and found there was nothing in the fridge or the cupboard. She told her aunty that she was just going home to make sure that her children had all gone off to school and returned with some tea, bread, butter and jam. Beryl asked if aunty was eating well and she replied that she was fine during the week and had meals with her family over the weekend. While they were talking, the aunty asked her to have a look in a drawer for her and when she did so, Beryl found letters from Income Support dating back six months, requesting her aunty to go in to renew her super. She had not done so and had had no money for the past six months. Beryl told her to get her hat and there and then took her into Income Support. Income Support managed to assist and pay the money that aunty had not claimed. The family were gutted when they found out as they had no idea their mother was living like that."

"There were so many stories like that. Another old man living in the community was so grumpy all the time. No one wanted to go anywhere near him. He would growl at everybody. One of the workers managed to make friends with this old man and realised that he was deaf. She asked him what would make him happy and he responded that he missed going to the marae and the hui. He must have been feeling very frustrated and isolated. She took him off, arranged for a test and then organised some hearing aids. The grumpy man became a very happy man."

Their quality of life was changed overnight. People didn't and still don't know what they were entitled to and neither were they told. THS and Hospice helped them to access assistance.

While Te Nohanga Kotahitanga is currently in recess at this time, support from Tūwharetoa has not changed. Today, the legacy of partnership and trust that Ratana and Peehi Wall grew is as strong as ever between the parties. It is important as both parties look to the future.

Sir Tumu says, "If we do nothing today then we fail the future mokopuna . . . "

Kamiria (Kim) Gosman



Left to Right; Suzie Kuper, Kaumatua Ratana Wall, Kuia Peehi Wall, Ros Gale 2007

# Challenges

Taupo Hospice had progressed significantly in the region since its inception. The Trustees were of the view that a Palliative Care Co-ordinator for the Lake Taupo District was critical to ensure that patient needs were met by all service providers. The Lakes DHB would make a contract payment to the Trust to cover most of the costs. In 2002, a decision to employ a Care Co-ordinator reflected that Lake Taupo Hospice's status under the Occupational Safety and Health Act had changed. Alison Rowe was appointed to this position, but she was to join Taupo Hospice early the following year.

The Trust continued to require significant funds for annual running costs. Once again there was a lot of activity organising fundraisers for the year. Margaret Shaw and her daughter, Robyn, produced a new recipe book, "The Bach in Winter" along the theme of the "Picnic Hamper', but with new and different recipes. Publicity regarding the care that Lake Taupo Hospice offered was an ongoing necessity and committee members spoke to many organisations.

Over that year, 2002 – 2003, the Hospice Home Support Team had 29 people referred to their service. Eighty-five percent of these people had a cancer related illness, and the other 15% had heart and lung disease or another terminal illness. Patients ranged in age from 25 to 64 plus years old, with the highest percentage being of NZ European ethnicity. Twenty-four percent of patients were of Maori and Pacific Islander ethnicity. The volunteers had averaged 140 hours and travelled an average of 455 kms per month to care for their patients. The average number of days a patient/family was in the Lake Taupo Hospice programme was 71 days with all day carer relief supplied by volunteers. At that time there were 32 volunteers registered with LTH. No income from Government sources was received.

Statistics from 2001-2003 complied by Hospice NZ showed about 8,000 people were cared for by hospices annually and at least another 3,000 terminally ill people were cared for in hospitals.

Jo Tinworth, a volunteer who had been involved with writing biographies for Hamilton Hospice, suggested that the same service should be offered in Taupo, and so another arm of service to patients was started. For a long time, Jo was the only biographer with Hospice.

In 2003 Katherine Gibson and Lexi Candy from Auckland came to Taupo to hold a weekend session on journaling and biographies. They presented an overall view of the process: how to commence and take to completion a biography with someone who was terminally ill.

The Bach in Winter

Compiling a life story with a biographer can be a most enjoyable process and provide the patient and family with a positive focus at a challenging time. The process of journaling was designed to help people discover memories they didn't know they had. It was an opportunity to record their life experiences, almost like keeping a diary, but in a structured format. The biography process would be recorded, typed up and bound, to present to the patient free of charge. This service continues to be an important part of patient care today.

At a meeting of the Lake Taupo Hospice Trust in January 2004, Liz Ranson resigned as Treasurer and Barbara Hickling volunteered to take on the role. A contract with Insurance Contracts was taken out to cover the Trustees, Volunteers and the Palliative Care Coordinator. The Trust was registered for GST and this took effect from 1st April 2004.

At this stage, the Trust did not envisage that they could establish full hospice facilities. The cost of running such a service was huge and they believed that their community could not sustain the ongoing financial burden. However, they could see the advantages in purchasing a residential property with good storage facilities, where they could incorporate offices, a meeting place, and a space to use as a day centre.

The Trust believed that there was a real need for a day care centre facility for palliative patients in the Taupo/Turangi area. These premises would ideally need to include a full kitchen and lounge area, counselling and administration rooms, place for education and training of patient caregivers and palliative care providers, storage of equipment and cleaning facilities, a place for patients to mix and mingle on a daily basis, an opportunity to provide day respite care for patient caregivers, an area for hairdressing and massage service for patients.

The Trust was interested in purchasing freehold land at the Hospital site and had discussions with the Lakes District Health Board regarding building a day care centre in the Taupo Hospital grounds. It was of the view that the building and furnishing would cost \$400,000 and they had \$200,000 in investment accounts. Annual running costs had increased significantly over the past two years and with a building, would likely increase further. They were prepared to commit up to \$150,000 to the project and applied to the Veta Mary James Trust for financial support.

In March 2004, a special meeting of the Trust was held to discuss a property which had come up for auction in Sunset Avenue. It would provide suitable premises for a Hospice Day Care Centre and was close to the Hospital. Amid much jubilation and with the very generous financial support of \$210,000 from the Veta Mary James Trust, the residential home was purchased by the LTH Trust. It was hoped that this purchase would allow the Trust to meet many of the needs of a day care centre.

Veta and Harry James resided in Orewa. When they relocated to Mt Maunganui, their Orewa home was virtually gifted to the Hibiscus Hospice and became their Centre. This was done in a low profile manner.

At Mt Maunganui, where Mr Harry James succumbed to cancer, they were both so grateful and touched by the help of the hospice there, that they resolved to continue their support of hospice.

Mrs Veta James passed away in 1999.

The Waipuna Hospice, Warkworth Wellsford Hospice and North Shore Hospice expansion have all been major grant beneficiaries from Harry and Veta James, having received more than \$1 million in total.

We will be incorporating a small plaque in our building to remember their generosity.

Alison Rowe joined the Trust as Palliative Co-ordinator in January 2004. Her role with the Trust was to ensure that the threads of all the palliative care service providers in the Taupo/Turangi district were brought together to ensure that the patients and family/whanau received the best possible service. This included clinical patient assessment, liaison and co-ordination with health professionals and other health support services. She was able to provide the home support team with knowledgeable guidance and support.

Alison initiated a pilot scheme for respite care for palliative patients with the Lakes DHB, which made \$40,000 available for a six-month pilot scheme. Support Net, an agency for assessing support services for people of all ages with disabilities, was to manage the administration of the fund and Alison, representing the Trust, was involved in the joint administration and assessment of the service. As from 1<sup>st</sup> July 2004, there would be one agency, Support Net, for respite palliative care and all home help services.

A Developing Education Programme was put in place and a separate Bereavement Group was established within the volunteer group. With the increase in workload, the Volunteer Co-ordinator's position became a paid role.

In February 2003, Robyn White was appointed to the Volunteer Co-ordinator position and it was agreed that the Trust pay her \$6,000 p.a., her telephone expenses and mileage. The Trust sponsored Alison, Robyn and a Taupo GP to attend the International Hospice NZ/Australian Society of Palliative Care Medicine Conference in Auckland which gave them an opportunity to gain more knowledge and contacts in palliative care.

Raewyn Officer, assisted by Jo Maling, took on the mammoth task of writing the required Hospice protocols. Other hospices were very generous in sharing material which Raewyn, who with her nursing background would then adapt them to LTH requirements.

The Trust, in conjunction with Hospice NZ and Genesis Trust, arranged breakfast meetings which effectively were video telephone conferences available to all people in New Zealand involved in palliative care. The breakfast meetings were well attended and the feedback from attendees was very encouraging.

In June 2003 Dr Libby Smales from Cranford Hospice, Hawkes Bay, repeated her visit of 2001 and ran two full day sessions covering amongst other things, Listening Skills, Legal Issues and Spirituality.

It proved to be a busy month as the Hospice acquired its own telephone number. This caused a lot of extra hours for a few volunteers who managed the phone over weekends and after hours.

# Turangawaewae - 7 Sunset Street

The purchase of 7 Sunset Street for the sum of \$445,000 was completed. With the generous bequest from the Veta Mary James Trust and a Choices Home Loan, the Trust took ownership on 8<sup>th</sup> June 2004. The Westpac Banking Corporation assisted with the purchase by agreeing to a loan of \$25,000 over a 15-year term at the interest rate of 7.75%.

Stuart Williams, along with a sub-committee, agreed to take over the running of the property and another sub-committee was elected to manage what furnishings were required. Alison agreed to lead a consultative team to suggest how the new premises could be used.

Reverend Wall blessed the Lake Taupo Hospice Trust home in Sunset Street on 23<sup>rd</sup> June 2004. The day went well and Ratana Wall suggested the house be named He Tohu-Oranga, meaning 'health foreseen'.

Initially, volunteer meetings held there required the volunteers to bring their own chairs and coffee mugs and the house was open one day a week. The house was to be used as a Hospice Family Centre rather than a Day Care Centre and once it was furnished, hospice meetings could be held there.



7 Sunset Street

Many people helped LTH Trust to achieve their goal of establishing a Hospice Family Centre. The Lion Foundation made a generous grant of \$15,000, towards furnishing Sunset Street. The furniture "wish list" included bookcases, tables, chairs, a settee, coffee table and freezer. Joanne Lewis of Lewis Consultancy, Veitch Morison Valuers and Wakelins Real Estate all donated their time, experience and fees, and all the neighbours willingly gave their written consent for the Trust to purchase the building.

The Taupo District Council granted a resource consent for the use of 7 Sunset Street as a Community Building in a Residential Area. The resource consent allowed meetings to be held there, and the use of the house as a centre for Hospice.

Jo Maling and a group of volunteers took on the responsibility for the Lake Taupo Hospice equipment which was now insured for \$36,000 and carried an excess of \$300. They terminated the renting space for the equipment with Strettons. Helpers sorted, identified, labelled, cleaned and valued equipment which had been moved from the storage room in town to 7 Sunset Street. It made sense placing the equipment closer to the hospital as the District Nurses selected the required equipment to go to a patient's home.

The Trust made application to the Pub Charities in 2004 for \$178,661. The application was for new equipment, furniture, debt retirement on the Hospice Family Centre, books and videos, volunteer funding, a car for the volunteer co-ordinator and to assist with the alterations to the house and driveway. Pub Charities gave the Trust \$56,535, enabling the debt of \$25,000 to be repaid.

At the Annual General Meeting of the LTHT on 16<sup>th</sup> September 2004, the following Trustee Appointments were made:

Taupo Medical GP Association:
 Dr Peter Battersby

• CEO of the Lakes District Health Board: Julie Eilers

• Lake Taupo Friends of Hospice Inc.: David Maling/Jan Wynn-Williams

• Tūwharetoa Trust Board: Ratana Wall

Gary Chapman was elected as Chairman, David Maling as Deputy Chairman and Howard Wedekind as second Trustee. Edna Walker was elected as Secretary and Barbara Hickling as Treasurer. Iles and Campbell were elected as Auditors.

The Palliative Care Co-ordinator, Alison Rowe, had been working a three-day week but her workload had increased significantly. She met with Leonie Pritchard from the Lakes DHB to discuss hours needed for the position and following on from this discussion, the position became a fulltime role.

The LTH Trust Inc officially opened its new Centre on Saturday 4<sup>th</sup> December 2004. Mayor Joan Williamson-Orr opened the House. A press release was prepared for the Opening Day and residents of Sunset Street were invited to visit to hear about the future plans for the centre. What a day to celebrate! The investment of so much energy, dedication, hard work, many years of fundraising and huge community support had succeeded in establishing a permanent place to call home for Lake Taupo Hospice.

### Consolidation

A meeting was called in January with an agenda to place advertisements as well as to discuss employment contract details for the appointment of a Palliative Care Co-ordinator, an Administrative Assistant and a Volunteer Co-ordinator. Alison Rowe thought it would be advantageous to have two people in the Palliative Care position to provide cover and support. Julie Eilers and Alison Rowe updated the job description and Gary Chapman updated the application form. The advertisement was sent to Hospice NZ and advertisements were placed in various newspapers.

The Lakes DHB was to provide \$20,000 per annum for an Administrative Assistant for the Palliative Care Co-ordinator. Advertisements for the role, the Volunteer Co-ordinator role and information about Hospice and its expansion in the area were run in the newspapers in February, with a closing date for applications of the 15<sup>th</sup> February 2005.

The Cancer Support Group, run by Jacky Gartner, began to use the house on a Monday morning once a month for the Cancer Society Coffee Morning. Initially the house was open one day a week for Hospice. The first Volunteer meeting for 2005 was held at the Hospice Centre on the 9<sup>th</sup> February.

Hospice equipment was now stored in the garage at Sunset Street where electricity and hot water made life a lot easier. Stuart Williams agreed to manage the house and ground maintenance, Robin Kidd built racks for storing the beds and mattresses, and Stan Shearer fitted latches and locks where necessary. Delivering and collecting beds was proving to be problematic with no dedicated attendant to do this. David and Jo Maling, who had been ably managing the equipment, were very supportive and stepped in to assist.

Alison Rowe arranged for Jo and David Maling to meet with Alan Stretton at his workplace. Alan managed the equipment for the Waikato Hospice. In March 2005, Alan valued all the existing equipment for the end of year audit and made several suggestions to manage the Hospice equipment which included:

- Organise a disclaimer form for all Hospice equipment which was loaned.
- Organise a flow chart and system for returned goods (cleaning and dry cleaning).
- Arrange twice yearly electrical compliance tests of all equipment by a registered electrician.
- Work out an arrangement for Hospice equipment held at the Hospital.

A van for transporting the equipment was becoming necessary as David Maling's trailer was being used. John Dickson agreed to assist with the delivery of equipment, but Hospice needed more volunteers to assist with deliveries and the cleaning of equipment.

The PHO in the Taupo area had commenced a new initiative in palliative care. From the 1<sup>st</sup> December 2004, GPs would receive a payment for patients referred to Hospice. Time would tell what impact this was to have on the relationships between GPs and the Hospice.

Dr Dave Nixon, Taupo Health Centre, raised a few issues that he requested the Board to approach:

- Palliative care bedside nursing support. No continuous 24-hour nursing care was available in New Zealand at that time. Funding for up to \$150 per day per patient, for a restricted period, was available through the DHB. Dave Nixon proposed that the Hospice allow a small budget to top up the ability to have 24-hour nursing care at home, which would mean that \$5,000 be set aside as a cash fund to top up the nurses' pay for additional hours.
- Specialist Oncology in Taupo. Dave Nixon requested Hospice write directly to Cathy
  Cooney to request funding to push for a medical oncology clinic in Taupo. This
  became necessary as waiting time to see the oncologist in Rotorua or Hamilton was
  around 12 weeks.
- Malulani Trust. Dave suggested that Malulani Trust may assist in the funding of 24hour bedside nursing services in special cases.

In a meeting with the Lakes District Health Board (LDHB), in December 2004, the increased demands on the Palliative Care Co-ordinator were discussed and agreement reached that the number of patients had increased approximately threefold. It was realised that unless the Palliative Care Co-ordinators' hours were increased, service demand would not be met. The LDHB agreed to increase the Palliative Care Co-ordinator appointment twofold from a 0.5 appointment to full time and to provide a 0.2 administration assistance. The increase in the contract to \$100,000 p.a. would start from 1st January 2005.

The Lakes DHB was of the view Lake Taupo Hospice was overpaid and would accept a refund of the contract of nothing less than \$15,000 from the amended 2004/2005 rate approved in December 2004 and would not accept an increase in the contract rate of more than 3%. The Trust felt an increase of 5% per annum for each of the past two years would be fair and equitable, and equate to an increase of the contract rate from \$100,000 p.a. to \$110,250 p.a.

The Trust had a legal and moral commitment to their new Palliative Care Co-ordinator and Administrator to continue their employment for at least twelve months. The Trust was forced to accept the contract terms the Lakes DHB dictated but was not prepared to enter into a contract beyond 1st July 2006.

Lake Taupo Hospice advertised for a fulltime Palliative Care Co-ordinator and part-time Administrator. No mention had been made at the meeting in December 2004 of the fact that if LTH could not have the full-time appointment up and running immediately then they would be at risk of being asked to refund the extra \$5,000 per month.

Judy Dinnis took on the role of Volunteer Co-ordinator early 2005. Following an article about Hospice in the local paper, new volunteers had called in to offer their assistance and the Trust suggested that police checks on all new volunteers be carried out.

Teresa Griffen was appointed to the Palliative Care Co-ordinator position and Haidie Burchell-Burger appointed to the Palliative Care Administrator position.

During this period, the District Nurses were contracted to carry out any palliative care work. The District Nurses worked from the Taupo Hospital. Julie Eilers, the Hospital manager, suggested that to build synergy with the District Nurses, that both Teresa Griffen and Haidie Burcher-Burger should have an office at the hospital. This made sense to the Lake Taupo Hospice Trust who agreed. In a practical manner the arrangement didn't work.

Teresa came from a dedicated Hospice where the sole focus was palliative care, end of life care. The District Nurses were primarily responsible for district nursing, assisting patients back to normal health. The District Nurses were excellent at dealing with end-of-life care, but time constraints with their heavy workload meant some frustration occurred between management and operatives over timely responses.

Sunset Street, where Hospice House was situated was creating an ambiance more in line with other hospice's ideas. To all intents and purposes, it was a residence, a home away from home, where people nearing the end of their lives could get away from the hospital medical environment.

As the office at the Taupo General Hospital was not suitable for both Teresa and Haidie, the new palliative care staff, they shifted the headquarters to the Hospice House in Sunset Street, which involved some expenditure. The purchase of a car for Teresa, the Palliative Care Co-ordinator, was proposed which brought the expenditure for new staff to \$41,000. A Hyundai 5-door hatch was purchased and stored at the Hospital.

The move away from the hospital for the Palliative Care Co-ordinator and Administrator was not sufficient to restore a happy work environment. In September 2005, Haidie resigned as the Palliative Care Administrator and Ros Gale was appointed to the position. The Malulani Trust was wound up and gave Lake Taupo Hospice \$20,000.

An AGM was held on the 19<sup>th</sup> September 2005 at which Gary Chapman vacated the Chair and David Maling was elected Chairman. Gary had led the Trust competently since its formation in 1986, doing a tremendous amount of work establishing the Trust and dealing with the negotiation of the contract with the LDHB. He agreed to remain on the Trust Board. Other Trustee appointments were:

- Dr Peter Battersby Taupo Medical General Practitioners' Association
- Julie Eilers CEO of Lakes District Health Board
- Chris Carl and Jan Wynn-Williams Lake Taupo Friends of Hospice Inc.
- Ratana Wall Te Nohanga Kotahitanga o Tūwharetoa

Edna Walker was elected as Secretary and Barbara Hickling elected as Treasurer. Iles and Campbell were elected Auditors.

Teresa Griffin resigned as Palliative Care Co-ordinator in October 2005. David met with Julie Eilers, Support Net, District Nurses and Leonie Pritchard to discuss a temporary replacement for the role for three months. The DHB's view was that the role should be expanded to encompass the whole Hospice role, using the Hospice philosophy and it was proposed that a subcontract for temporary Palliative Care services be given to the Taupo Hospital up to 17th February 2006.

The rapidity of changes in palliative care staff did cause concern in the wider Hospice family. There were also questions as to how to manage the environment in which people were expected to work. The introduction of a more "pro-active hospice" was to all intents and purposes, wrestling a place in the established medical world of the community. This was not the sort of start that Hospice had wished for.

In early 2006, Judy Dinnis, the Volunteer Co-ordinator's, contract of employment was discussed. The contracted hours of employment were increased from 10 to 15 hours per week and the Trust agreed to pay 40c per kilometre for mileage. Judy's hours were increased from 15 to 20 hours per week in July 2006. Her hours were once again increased from 20 to 25 hours per week in November 2006.

Through networking, good relations had been built with the wide geographical spread of hospices. Other hospices who were also in the development phrase, had faced the challenges Taupo Hospice was facing. David Maling was grateful to Janet Whiteside, who was the incumbent CEO at Rotorua Hospice, for playing an important role in guiding management. She would come through to Taupo in her own time and there was no charge for her generous guidance.

The tenets of her discussion were:

- 1. The Hospice philosophy needed the support of the wider local medical fraternity, the general practitioners.
- 2. That Hospice needed to find a person to be care co-ordinator from within the district. The preference should be towards someone known and respected amongst the medical community. Hospice would need a person who understood and accepted the diverse range of people who were under Taupo Hospice care.
- 3. That Hospice needed to use nurses trained in Palliative Care.

Coupled with Janet Whiteside's support was the encouragement of many of the local general practitioners.

Julie Eilers and Howard Wedekind resigned from the Trust. Laurie Burdett joined the LTHT as the Lakes DHB representative and the new Trustees Wah Mclean, Maurice Gianotti and Chris Carl were welcomed. Jan Wynn-Williams retired, and the Volunteers appointed Wah McLean as their representative on the Trust.

The Trust now focussed on its aims for the year:

- To be a leading source of Palliative care in the Taupo region.
- Implementing procedures necessary to support the LDHB contract.
- Exploring, with all ethnic groups, ways to improve the effectiveness of Hospice Care.
- Seeking to further support the valuable work of the Doctors and District Nurses in dealing with Palliative Care issues.
- Identifying opportunities and funding streams that allowed Hospice to meet future community demands.

At the AGM held in July 2006, David Maling was elected Chairman, with Maurice Gianotti as Deputy Chairman, Gill Jones was elected as Secretary and John Wallace was elected Treasurer. Gary Chapman resigned from the Trust.

The hourly rate, wages and salary were increased for the Palliative Care Co-ordinator, Administrator, and the Volunteer Co-ordinator.

Staff and volunteer training continued, with attendances at a cancer workshop in Rotorua and a volunteers' meeting in Turangi. A donation from Bay Trust was used to train people at Taupo Hospice to record biographies for patients. Three dictaphones and transcribers were purchased for biography purposes with some of the funds received from Pauline de Lira's Cabaret. Volunteer Specialist Services were now in great demand. These included Jo Tinworth (biography), Derm Buchanan (counselling), Raewyn Booth (hairdressing), Carol Davidson and Deborah Jay (massage) and Merril Ridley (podiatry).

Chairman Chris Carl led the Friends on further fundraising ventures. The film 'The White Countess' filled the seats of Starlight Cinema early in the year and in October, only an hour after the world premiere of the film 'The World's Fastest Indian' in Invercargill, Taupo Hospice held its own premiere of the film. Peter Smith's generosity and the wine and nibbles arranged by Judy Dinnis and Janet Willis ensured that there was capacity crowd and a cheerful audience who were happy to contribute \$3,500 to funds.

In October 2006, the Friends held a very successful auction which netted \$38,000. A lot of effort to organise this event was put in by the committee, Hugh Treadwell and the Cooper family. With morning teas, sales of recipe books and funding from community awards, they were kept extremely busy. The wife of Taupo Mayor, Lynn Cooper, one of Lake Taupo Hospice's staunchest supporters stepped down from the committee after twelve years of willing service and was replaced by Graham Pringle.

A contingency fund was set up in a bid to keep a six-month fund in hand as a buffer for the future. The need for a storage facility, maintenance of assets and possibly the need to employ another part-time palliative care person had to be considered. It was decided that the reserves be made up of a six-month period of income to cover wages of \$75,000 and a Hospice House improvement fund of \$36,000.

With the Trust hosting a Christmas lunch for the general practitioners, district nurses, Friends and volunteers, sales of Christmas Candles and a garden party held at the home of Chris and Paddy Carl, 2006 ended a busy and successful year for everyone involved with Taupo Hospice.



### **Role of the Palliative Care Co-ordinator**

"One day Jenny Stratton, a fellow nurse, shoulder tapped me and said, "Do you realise you will lose your practising certificate if you don't hurry back to nursing?" I had had a break from nursing for four and a half years at that stage. In my heart I was always a nurse and I could never let it go so I started in the emergency department at Taupo Hospital and then began working for the District Nursing service. That is how I became involved with palliative care. At that point Theresa Griffin, the second palliative care co-ordinator for Hospice, had resigned. They were struggling to replace her with someone suitably qualified with palliative care experience and Peehi Wall grabbed me in the corridor one day and said, "You are the one". I had a talk to Julie Eilers about it and although palliative care nursing was not in my background, I had 25 years of nursing experience and palliative care patients came into the ward. I had been the charge nurse for many years. I thought I could transfer those same values out into the community. The shock was yet to come because the reality was quite different. I was grateful for the likes of Janet Gainsford and Judy Tunnicliffe, who were district nurses at the time, to help and support me in this very new and isolated stand-alone role. My job was to go and meet with the family and whānau and see what needed to be done or what could be done from Hospice's perspective and join those dots together with the volunteer services."

Suzie Kuper

Suzie Kuper was appointed as Palliative Care Co-ordinator in November 2005. She had the support of the GPs and Palliative Care Support in Waikato and brought a wonderful energy, enthusiasm, and her ideas to Lake Taupo Hospice. The new contract was to be reviewed every twelve months and was to include study time, of which the Trust would pay Suzie's Te Omanga Hospice Course fees. Suzie's skills and positivity made an immediate impact and, together with the Judy Dinnis, the Volunteer Co-ordinator, and newly appointed part-time administrator, Ros Gale, the Hospice personnel were rapidly becoming an excellent working team.

Suzie continued to be employed by the hospital to overcome the issue that she did not have a Palliative Care background but worked from Hospice House. They didn't have many home care assistants who were trained in palliative care back then. Margaret Seal was working with district nursing and she was one of the home support team for around 20 years. Leonie Pritchard was the contract manager for community services for Lakes Districts Health Board. Leonie, Suzie and David Maling sat down to work out how to unbundle the funding as it was then, to make it meet the needs of the population.

In those days, half an hour was allotted for home help and so many hours for personal care and respite in a hospital. Some patients needed all the home help and meal preparation they could get but could still shower themselves. Others were tucked up in bed and only needed the personal care as family came in, took over the running of the household and meals. They just needed someone who knew what was going on to guide and support them.

With that in mind, they unbundled the funding into one big bucket on the contractual understanding that the Hospice nurses would go under the package for home care. The funding came from the DHB and that pool of funding and contract still exists today. It has been a flagship for the rest of New Zealand and has been enormously successful. Hospice doesn't have to administer that budget as Support Net does it through the DHB. It was a much more family/whānau centred way to structure things.

Suzie was initially employed by the DHB but working from Hospice House. About six months later, Hospice took over the contract. "I thought I knew what Hospice patients and family might want but the steepest learning curve for me was to go talk to those family/whānau and understand the situation from their perspective." Suzie Kuper

The volunteers came from all over the place in those days. Sometimes it was the spouses of patients who had died who still wanted to be involved and give back. It was a very tricky time for volunteers back then because the laws had changed regarding health and safety and so the Trust became a lot more liable for what could and couldn't be done. Volunteers were expected to step down from their role for 12 months if they had lost someone recently, but Alison Bowman and Suzie tried hard to dismiss that. They thought they should take it on a case by case basis because for some people, especially if they were working at something like the garage sales, it was their absolute god send. It was a great place to reestablish themselves in the community and make new friends. Some people would lose not just one but two or three people and had been caregivers for so long that they didn't remember what it was like not to look after someone. Hospice became not just a centre for patients and family care, but for good bereavement care too.

Ros Gale, the Palliative Care Administrator, headed south and Terri McCullum came on as her replacement. Terri was amazing, and nothing was ever too much trouble for her. She was the front face and always ready to find the right support for someone within the team. Alison Bowman, with her medical background, had a good understanding of what course the illness was likely to take for a patient. She could match her volunteers up expertly. Matching the right families with the right volunteers was critical.

Alison grew the volunteer service from 20 to 30 volunteers, to very much the number it is today. Monday morning meetings were crucial. We would all get together and discuss who was needed and where. Alison would be informed which families were going to need what sort of volunteer help.

John Wallace, treasurer of the Trust at that time, would pop his head around the door regularly to ask what we were up to. He always asked what was needed and how the Trust could make it happen. All these people had that strength-based mindset of 'nothing was impossible.'

Alison and Suzie made a concerted effort over the next five to ten years of going to every service group, talking about what Hospice did and how people could access those services. It quickly became apparent that Suzie's job was bigger than she could handle on her own. Suzie wrote a comprehensive report for the Trust on what the service could look like if the nursing service was fully under Hospice, if they owned the contract for the whole 24/7 support service as opposed to the current model which was split with care co-ordination sitting under Hospice, but the day to day district nurses being hamstrung because of what they could and couldn't do. There was about a \$60,000 shortfall but they felt sure once they were able to give that good wraparound service not only the DHB, but the whole community would see how worthwhile it was. The Creative Catwalk, fund raising events, bequests and donations would help to raise the money. That is exactly what happened.

### Excerpt taken from 'Report By: S Kuper, Clinical Manger (RN, ADN, MHC)':

#### **PURPOSE**

This paper is to inform stakeholders in Lake Taupo Hospice's clinical services on the current model of care. A "Model of Care" broadly defines the way hospice services are delivered, to whom, how and when. The model outlines best practice and services for hospice patients and their families/whānau as they progress through the end stage of life. The model describes the philosophies that underpin hospice palliative care, the current clinical services plan and expected outcomes. The guiding principles used to develop the model are that it:

- Is patient/family/whānau centric.
- Has localised flexibility and considers equity of access.
- Supports integrated care.
- Supports efficient utilisation of resources.
- Supports safe quality of care for patients.
- Has a robust and standardised set of outcome measures and evaluation process.
- Is innovative and considers new ways of organising and delivering care.
- Identifies gaps and sets a vision for services in the future.
- Links to Lake Taupo Hospice's strategic planning process, overarching clinical services policy (draft), and clinical services action plan (draft).

The model aims to ensure people get the right palliative care services, at the right time, by the right team and in the right place. The over-arching clinical services policy (draft), will sit below this model and outlines the associated legislation, best practice guidelines and MOH directives that are utilised in service delivery. The clinical services action plan (draft), then sits underneath the clinical services policy to describe the associated goals, activities and performance measures required of clinical services both now and into the future.

Describing the model of care helps keep the patient, and family/whānau at front and centre of services to improve the quality of end of life care, challenge traditional biomedical models and ownership, involve the community and give both consumers and frontline staff a voice in clinical service planning.

### Lake Taupo Hospice's Vision, Mission, Values and Philosophy

In 2010, significant foundational work was done by Lake Taupo Hospice Trustees, staff, volunteers and a consumer focus group with direction and support from external strategic planning consultant Terri Foley of Jabiru Business & Marketing Consultants, to formulate the first organisation wide strategic plan. As part of this process and in response to surveys and face to face interviews with the Trust, staff, volunteers, external stakeholders, patients and their family/whānau, the following vision, mission, core values and philosophy were agreed.

#### Vision

'Living Every Moment' - is aligned to Hospice NZ in agreement with Hospices nationwide.

#### **Mission**

Lake Taupo Hospice strives to be a patient and family/whānau focused centre of excellence for providing specialist palliative care to all those with active progressive life limiting illness. We recognise diversity and act professionally with compassion. We work in partnership with our communities and other health service providers to ensure that our patients may live every moment and die well supported with dignity, and where possible, in the place of their choice.

#### **Values**

Excellence: valuing leadership, education, innovation, advocacy and quality

- Respect: valuing honesty, thoughtfulness and consideration
- Trust: valuing reliability, fairness, truth, responsibility and competence
- Partnership: valuing collaboration, friendship and consultation
- Compassion: valuing empathy, concern, kindness, caring, faith and hope

## **Philosophy**

"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 Cecily Saunders Founder of the Modern Hospice Movement: 1960

At the heart of all hospices is the WHO Palliative Care philosophy of care that:

- Affirms life
- Recognises dying as a natural process
- Adds life to the days, neither hastening or postponing death
- Promotes patient choice and autonomy
- Care is family orientated
- Provides relief from distressing symptoms
- Recognises grief as a normal response to loss and support for the family continues into the bereavement period
- Access is needs based and care is culturally appropriate
- Integrates physical(tinana), social(whānau), emotional(hinengaro), and spiritual(wairau) aspects of care to help the dying person and whānau/family attain an acceptable quality of life
- Offers help to the whānau/family, carers during the person's illness and bereavement.

## **Demographics**

Lake Taupo Hospice serves a population of 33,000 people over a large rural and provincial area in the southern half of Lakes DHB. Lakes DHB has a total population of 105,170 people of which LTH services about 1/3. This has formulated the historical basis for the 2/3 to 1/3 population-based funding split between Rotorua and LTH's by Lakes DHB, although it has been argued that we have a much bigger geographical spread and higher associated costs.

### **Ethnicity**

27% of the population identifies as Māori, however only about 13% of Māori are in the 55yr and over population who would be most likely to require palliative care. The percentage of Pacific Islanders (2.9%) and Asians (0.2%), is low compared to the rest of NZ, however the Asian population is expected to grow with migration away from Auckland.

#### Geographical Area

Lake Taupo Hospice covers a wide geographical area including northern national park, the Western Bays and out to Tarawera. Reporoa is in the main covered by Rotorua Community Hospice, exceptions are made from time to time when the family ties and GP are based in Taupo or when either team is already seeing patients close to the boundary. Mangakino, while within Lakes DHB, has palliative care domiciliary nursing and community services from the District Nursing Service in Tokoroa. Lake Taupo Hospice supports these nurses with 24/7 phone advice and co-ordinates the Palliative Medicine Specialist to visit when needed.

#### SUMMARY

Lake Taupo Hospice's model of care has evolved from a home based domiciliary nursing model to a holistic model that includes a range of psycho-social and volunteer services where the emphasis is on the person and their family being able to choose which parts of the service they need and when. There is a much greater emphasis on palliative care education across the spectrum and providing support and advice to primary palliative care providers in aged residential care, hospitals and home-based support services. Volunteers and homebased support staff play a critical role in assisting families to feel safe and cared for. Such a wrap-around model as Lake Taupo Hospice has today is a very fitting cloak for Taupō nui a Tia.

Hospice received permission from the DHB to employ another nurse co-ordinator. After two unsuccessful appointments, Janet Gainsford came on board. Janet was the pinnacle of what palliative care nursing care looked like in the terms of compassion, knowledge and providing the way for families. Just being there to be that present person who knew what was going on. She was terrific and we all miss her to this day. She died in the arms of a volunteer who had just lost her husband so that was both tragic and special to us.



L - R Nurses Suzie Kuper, Vicky Townley, Judy Tunnicliffe, Janine Colpman-King, Janet Gainsford

Hospice received funding from the DHB for education. Janine Colpman-King took on the role as Clinical Nurse Educator to develop education programmes, to facilitate the Liverpool Care Pathways and implement it appropriately. It was a support system and tick boxes were there to check that all the people who needed to be in the loop were informed, the correct medication was being prescribed and the right equipment was on board. No stone was left unturned.

Te Ara Whakapiri was the philosophy. It seeks to focus on delivering the very best care for people who are dying and for their family/whānau, whatever the setting. This toolkit has been developed to enrich and support delivery of end-of-life care throughout the country.

Sunset House was beginning to explode. Staff were having to use the laundry as office space, and "they were virtually sitting on each other's knees." Maurice Gianotti and Tony Bowman converted the garage, so the nurses became the "garage girls"- with much hilarity.

There was a very happy feel to Sunset House and of course, Tūwharetoa was alongside right from the get-go, especially Ratana Wall in engaging Maori community and the gifting of money to assist us. Peehi Wall was also a regular at the house. Putiputi, Peehi's daughter, was on the Trust for a while too. Another gentle soul.

### Whakatauki

Naku te rourou nau te rourou ka ora ai te iwi.

"With your basket and my basket, the people will live."

Maggie Pleydell and Elaine Larsen joined the nurses. Elaine was Tūwharetoa herself. Maggie was from up north and even though she was Maori it was a bit more difficult for her in the iwi. Both were hugely instrumental in engaging Maori communities. Some families' living conditions were really tough. Christine Clark came on board and her background was cancer care and chemotherapy. Hospice didn't have any specialist cancer care nurses at that stage and of course many patients today have elective or alongside palliative chemotherapy. She brought that lovely facet to the nursing and then Annabel Jeffery joined the team with her background in cardiac nursing, of which she had in-depth knowledge. Hospice had this effective team of people who all had various skills. Suzie's role became the Clinical Services Manager and she was to be in the centre of everything, employ the right people and keep the wheels turning smoothly.

In about 2008, when more funding from the Minister of Health was received, Lake Taupo Hospice arranged for the Palliative Care Medicine Specialist to visit one day a month. Specialists at Waikato would come down and case by case help the GPs, give advice and support to the nursing team, and open education between the doctors. They stayed in Taupo overnight and provided a round table conference, so the shared learning continued, and continues to this day. A full time GP would only see about 15 to 20 patients dying in a year. Every end stage disease follows a different course and experienced nurses know that. This is where they are needed to support the inexperienced GPs and help get the specialists involved. "It is one of the best models I have seen anywhere for keeping GPs informed." Suzie Kuper

The CEO of St. Christopher's in London came out for one of the Hospice conferences one year. She said, "It is not more skilled people that we need in Hospice and palliative care, but more multi-skilled people. Hospices must really learn to support all of their staff to broaden their knowledge, so that nurses get counselling skills, counsellors get supported to do their social work degree, and so on, so that we get that lovely cross over."

The patients, families/whānau told us they didn't want more cars in the driveway with different people from a variety of services, they would just like one person who knew what was going on and understood. Whenever possible the nurses would take Josie, our counsellor/social worker, with them when they went to meet a new family, so they would know her right from the beginning. For some families it is more important that the counsellor/ social worker or kaiāwhina is involved and the nursing care doesn't need to come in until later.

In those days Hospice was caring for mostly cancer patients, about 80%. As the years progressed, Lake Taupo Hospice could provide a broad range of services and by having so many volunteers on board, they could start looking at people who had been diagnosed with other things like motor neurone disease and other incurable conditions. The doors were then open to patients with heart failure, liver failure, it didn't matter what the palliative condition, the whole Hospice ethos nationally became it doesn't matter what you had, if it was life-threatening or life-limiting illness, then they would go in, meet with them, see what was needed and do whatever was immediate. If a family didn't initially need Hospice, they would know how to contact us in the years to come. Some patients only needed a monthly or three-monthly check-up, but they knew the team. They weren't strangers. Some needed the whole service right from the start.

2012 saw big changes in the DHB in the way they saw community services, Hospice and palliative care patients. It became a very task-orientated service. Lake Taupo Hospice knew the writing was on the wall for the home visiting service, that they were no longer allowed to visit when there was not a task to be done. There were several fairly traumatic incidents for families and patients where the optimal care was unable to be provided because of the contractual arrangements and it was very upsetting for everyone concerned.

Vanessa Russell was the Community Contracts Manager and she took over the contract for palliative care services. She was hugely supportive in everything the Trust have wanted to do, even though she was restricted in how Lakes DHB could help financially, but she certainly helped as much as she possibly could in making sure our processes passed audits.

### 8 Puriri Street

The decision of the Trustees to purchase 7 Sunset Street was a prudent one. The staff were full of praise for its convenience and the purpose for which it was used. Visitors to the house, including patients, derived great enjoyment from the comfort provided as the house was well appointed, well situated and had a pleasant outlook. It became obvious with time that there were two areas where more space was required. There was a need to relocate patient equipment from the Sunset Street garage as the Hospice car shared the equipment space. Secondly, there were five allocated vehicle parks, so the street was used when more parking space was required.

A section at 8 Puriri Street had come onto the market. It was a back section in Puriri Street which adjoined the Sunset Street property. The only building on the section was a 50 square metre double-door Sky Line shed, so there was spare room on the section for developing car parking. In the event of Hospice purchasing a vehicle/trailer for distributing equipment, the shed would accommodate both vehicle and equipment. It had been on the market for some time but had not attracted much buyer interest.

John Crystal and Stuart Williams inspected the property and strongly recommended that the Trustees agree to the proposal to make an offer to purchase. The Trust would own two titles alongside each other which would reduce the need to look elsewhere to alleviate some of the space problems. In February 2006, Lake Taupo Hospice Trustees purchased the section with a loan from Westpac for \$70,000. Improvements and alterations to the Puriri Street property were made using funds donated by the Lions Foundation.

Improvements were made in 2009 by way of an extra Sky Line garage to store equipment, provision of a gas califort for hot water, electricity and laying a cobble stone driveway using funds donated.

The double garage on the Puriri Street section was bursting at the seams with donated goods and it became clear that these would need to be stored elsewhere unless sold, as the space was needed for overflow of equipment from Hospice House. In the meantime, a large table from Pak 'n Save had been made available to help with the problem of overfill.

Garage sales became one of the primary fundraising activities, being held every Wednesday morning and operated from the double garage. They were run entirely by a team of nine volunteers with four to five volunteers turning up each week to sort and sell the donated articles. One of the volunteers was responsible for collecting large items from people who were unable to deliver them and yet another volunteer, with electrical experience, checked all the donated electrical appliances to ensure they were safe.





Early days at the garage sales in Puriri Street

Business was booming and by May, with Wednesday garage sales collecting an average of \$100 per week, it was decided to have a Saturday sale on 19<sup>th</sup> of the month as well. This was to be the start of further, very successful Saturday sales. Stuart Williams stressed the need to think about opening a Hospice shop on the premises.





L-R Liz Connell, Kenya Eddy, Val Arnold and Helen Scanlan

### **Volunteers**

Volunteering is offering to do work for no compensation or remuneration and people tend to volunteer for organisations that have a personal meaning for them, a cause they are passionate about and in a role that gives them fulfilment. Right from the very beginning when the dream of a hospice in Taupo was in its infancy, volunteers have committed hundreds of hours, energy and passion into making this dream into reality. Their aim has always been to provide care and support to the terminally ill and their families so they may live life as fully and as comfortably as possible. Volunteers have been crucial to the success of Lake Taupo Hospice (LTH).

Over the years, dedicated co-ordinators assisted and supported the volunteers in their various roles which included caring, fund-raising, visiting, cooking, baking, gardening, maintaining and delivery of equipment, managing the finances, and all the myriad of tasks that encompassed keeping hospice as an integral part and service in our community.

As LTH grew, they saw the need for paid employees and by 2008 there was a paid Volunteer Co-ordinator, Palliative Care Co-ordinator, a part-time Administrator and the Tuesday Club Co-ordinator. Judy Dinnis had resigned, and Alison Bowman was appointed to the role of Volunteer Co-ordinator.







Alison Bowman

The Lake Taupo Hospice Trust funded Alison to attend the National Volunteer Managers' Meetings with Hospice NZ, as the Trust knew the value of the volunteers and understood that the Volunteer Manager needed to represent them at a high level. At these meetings, Hospice NZ was very enthusiastic about changing the title of Volunteer Co-ordinator to Volunteer Manager, which they felt would give the volunteer role and services a higher status.

The Trust agreed to the change in name and the following year, the title formally became the Volunteer Manager of Volunteer Services. It was designed to reflect that the role wasn't just about managing the volunteers. It encompassed setting up the orientations, the training, the database, and various services.

The most important part of the job was to help patients "live every moment". By utilising the skills and talents of the volunteers, which included all the fundraising efforts too, to help the patient to live every moment, Lake Taupo Hospice needed the funds for all the services offered. Hospice was there for the patient.

Also, of huge importance was to train volunteers in their specialist roles. Alison thought it was inappropriate to have volunteers, specifically the ones who were going to see patients, not having an understanding of what Hospice could offer and also the training in the grieving process, how the patient may be feeling and how to handle it. She felt it was unfair on the volunteers to put them in those situations without the appropriate training.

An orientation for every new volunteer was held once a month and it was expected that every volunteer, including all new Trustees, would attend orientation before they took up any role in Hospice. Everybody attended orientation and there were usually between four and twelve people attending once a month. The very new volunteers got to know other people starting at the same time as well, which made a difference. There was also specialist training for volunteers who visited patients. It was expensive to send volunteers away to get trained, so Alison and a couple of volunteers set up a training programme, which was a great success. It was also good to have the input from volunteers from other hospices who attended the training.

"I could not have achieved what I did without the support of the Managers of other Volunteer Services in Hospice NZ. The presentations were good and all the interaction between the other Managers was fantastic. I had so much support and help. It kept us all thinking about what we were doing and being accountable. There was a lot to keep track of with so many volunteers". Alison Bowman

All the administration of the volunteers such as the police checks, OSH training, health and safety, etc, took a lot of time. Betty, a volunteer, came in once a week to update the database and Dorothy, also a volunteer, helped with the police checks. The Manager was also an advocate for the volunteers in the community and the Trust. It was so important to promote the number of hours the volunteers did, the difference they made to patients' lives, their value and commitment, because the services the volunteers offered could easily have been cut from funding. The volunteer services allowed Hospice to highlight to both Government and DHB funding personnel, how significant the volunteers input was, and it was something they were not being asked to fund.

Another important role for the Manager of Volunteer Services was to ensure that all the volunteers felt appreciated and valued. It was probably one of the more challenging aspects of the role because people volunteer for so many different reasons. The Manager had to get to know every volunteer in a general way, to better understand their interests and talents, and know what they wanted to achieve through volunteering.

Some of the ways this was achieved was by developing a database of volunteers. In 2008 Hospice had around 50 volunteers, all patient-orientated, either visiting, helping with Tuesday Club or some doing podiatry and massage. Alison Bowman initially had the volunteers on a spreadsheet, which had its limitations. Through the Hospice NZ meetings, she found there were two or three different databases available for volunteer management and the Trust agreed to purchase one of them. It was a huge job initially getting all the volunteers onto the database but after about two months, and with Alison being adept at configuring the database to suit the Hospice, she could use it to find volunteers and match them to tasks, or match volunteers to patients.

In addition to the above, the database also allowed for greetings to be sent to each of the volunteers on their birthdays and the anniversary of their joining. It was another opportunity to say thank you to them and it was a gesture that was much appreciated.

"That made my job so much easier and made reporting so much easier because I could work out how many people had done various jobs like gardening, cooking, etc so we could see where funds were needed. It was an absolute bonus. It improved my efficiency in managing the volunteers. Some volunteers had jobs or worked various days and I was able to set up fields to incorporate that sort of information. In the notes I would have a history of people the volunteers had worked with, volunteer interests and the opportunity to offer them tasks they enjoyed, and which were most needed."

Alison Bowman

Every Monday morning, all the nurses who were available that day, Josie from the bereavement team, and Alison would discuss and report on every patient. They would talk about what had happened during the week, if volunteers were needed, what stage the patient was at. It was time consuming, but a valuable use of time and a good way of keeping up with the patients every week. Following that, Fiona, the Tuesday Club Co-ordinator would be given a list of everybody who the nurses thought might like to be invited to Tuesday Club. She would ring them all and then inform Alison which patients had transport requirements. Some drivers collected people for the Tuesday Club on a regular basis, and the co-ordinating from all angles for Tuesday Club was quite extensive.

"In those days all of the senior leaders used to go along to the Trust meetings once a month. We were able to report to them directly but that changed. The new CEO requested the leaders give their reports to him, and he co-ordinated them and presented them to the meeting. I think it would have been nice to go to every third or fourth meeting as I think the Trust lost the ability to question the managers themselves."

Alison Bowman

Some of the volunteer services were assisting in the Hospice Shop, Tuesday Club, patient visiting, hairdressing, beauty therapy, biography, gardening both at Hospice and at patients' homes, massage, library, equipment delivery, pick-up and delivery for the shop, maintenance team for both the shop and equipment, fund-raising, baking and cooking, podiatry. A bit later the grief counselling service was added. None of the services could have been offered without volunteers.

Some hospices felt the volunteers in the shops were retailers, had nothing to do with patients and therefore were to be treated differently from the other volunteers. Alison felt that every volunteer should be an advocate for Hospice. "Even in the shop, someone could walk in and ask for help. If those volunteers didn't have any idea of the services offered, they should be at least able to give out a brochure and some information about Hospice, otherwise a huge opportunity would be missed." All the volunteer shop assistants used to attend orientation as well and they knew how Lake Taupo Hospice was funded.

Initially there was a generic application every year to the Trust Power for various awards for volunteers. They didn't seem to get much traction but then Alison started to present a different group every year for an award. One year the equipment delivery guys, one year the biographers, another year the Creative Catwalk, etc, and that was very successful. The Creative Catwalk won the supreme award one year. It was great publicity, good to get the awareness of what the Hospice volunteers were doing out into the community and it was nice for the volunteers to get that appreciation.

During volunteer appreciation week Lake Taupo Hospice hosted a party for the volunteers. It got bigger as the years went by and was so much fun. It was rewarding to see everyone come together and probably the only time the volunteers got to see the Trust members. The nurses and Trust would always come along and talk to the volunteers. The Christmas party at the end of the year was shared with the staff and the Trust.

The awarding of long service awards, five and ten years, was initiated as part of the Volunteer Appreciation Party each year. It was decided that this appreciation would be in the form of specially made badges.

The numbers required made them quite expensive, so Alison reached out to the Hospice NZ group of Managers of Volunteer Services and nearly all those who used the Hospice NZ "kowhai branding" joined in to do bulk ordering which brought the price down considerably.

The Friends of Taupo Hospice had always been a group of volunteers who got together to fund raise for LTH. With the introduction of a paid Fundraising Manager at Hospice it was decided that it would be an appropriate time to change the name of the group to more correctly reflect their role and prevent any confusion of roles in the community. The Friends of Hospice became the Event Committee and the "Friends" were community members who made regular donations.

An annual "feedback form" was sent out to volunteers. This form asked some specific questions and provided an opportunity for each volunteer to say what they loved about volunteering at Hospice, and how they thought the service could be improved. Some great feedback was received and from that several small improvements to the service were able to be made. It was about making sure that the volunteers felt they were involved. Volunteers can offer valuable feedback and want to help their organisation as much as they can.

"Our lives are shaped as much by those who leave us as they are by those who stay. Loss is our legacy. Insight is our gift. Memory is our guide."

# **Tuesday Club**

"The first lady I met when I started as the new Palliative Care Co-ordinator, was Nancy Maniapoto, a beautiful, elderly kuia living with her two daughters and family in a little house. She told me that everyone else in the whanau was getting to go to a Christmas Party except her. She said that she had not been out of the house for a social engagement for so long. When I asked her what Hospice could do for her, she replied, "Please make me a party." It was the last thing I was thinking of. I went back and asked Judy and Ros if we could organise a party in three weeks. They said, "Of course we can." Nancy really taught us a lot about the meaning of social wellness, and she was instrumental in us getting the Tuesday Club up and running. We had that first party on a Tuesday and a Tuesday it has stayed. So, it became the Tuesday Club and through that we made sure it was Christmas every week for these people."

Suzie Kuper

In 2006, Suzie Kuper initiated Tuesday coffee mornings at Hospice House. These proved to be popular. As they became busier, transport was required for some of the patients who wanted to attend. It was also suggested that the mobility taxi be engaged to transport the wheelchair bound people.

As these coffee mornings grew, it was decided to look at employing a suitable person to run them and organise the day. The Trust agreed to employ an Activity Programme Coordinator and Robin Angell-Morice (Bobby) was appointed to the position of Activities Coordinator. A massage therapist began attending the Tuesday session on a voluntary basis and that proved popular too.

An active group of volunteers namely Jill Keith, Jo Maling, Daphne Emery, Jill Crequer, Dianne Maxwell and Bernie Holly from Turangi, would meet and greet the attendees. The team of volunteers would mingle and talk with the patients and, at the same time, provide very appetising morning teas.

June Crawford very kindly donated her piano. June loved music and loved to play. Singalongs were popular and there was never a shortage of someone to play. Alan Payne was often invited to sing and play for the Tuesday Group.

Peter Mcintosh, a colourful personality, along with Pay Vesey, would lead the Bingo and Uno sessions providing a lot of hilarity.

As patient numbers grew, the coffee mornings at Hospice House developed into the Tuesday Club. Welcome morning teas were provided which were followed by an activity or entertainment of some kind and the morning wrapped up with a lunch.

Apart from the Activities Co-ordinator, all the people who put this day together were volunteers. A team of three or four ladies would prepare food at home and then come along on the Tuesday to serve it and clean up afterwards. Another two or three volunteers would join in the activity and assist with the clean-up. The activities or entertainments were carefully selected to either promote creativity or to provide a jolly good laugh, both essential for the enjoyment of life.

One year the Tuesday Club members made "cat blankets" for the SPCA and entertainment included things like: Bingo, card making, rugby quizzes, making cat cushions for the Hospice Shop, hats for Melbourne Cup day, pub quizzes, making Easter and Christmas decorations, Valentine's celebrations, painting, pottery and visits from various groups. One year the Taupo Language School taught the members how to eat with chopsticks at a Chinese New Year festival, along with a Chinese meal. Another time it was an Italian meal and talk on Tuscany. They were treated to talks and entertainment along with a magician show by Bill Seagraves.



Melbourne Cup at the Tuesday Club

Joe Ridley had been alongside Hospice for many years as their ultimate handyman. Whenever a shelf needed to be put up or anything hung up, Joe was the man to call, even helping patients and families do little bits and pieces. He volunteered for Tuesday Club helping to build bird boxes for families or traps to set up in gullies.

Christmas always provided much laughter and fun with a beautiful Christmas lunch, pulling of crackers, jokes and wearing funny hats. A lot of sharing along with the fun. When you sit down to a meal it seems to break down all those barriers. The Tuesday ladies supplied amazing food, and the patients and their families got to talk to each other too.



Christmas Lunch at the Tuesday Club

Tuesday Club provided, and still provides, many benefits. Patients and their families were able to have a social outing where they felt secure in the knowledge that people understood and supported them. If caregivers chose to, they could leave the patient at Tuesday Club and do their own chores or social activities, secure in the knowledge that the patient was well cared for.

One patient was anxious about attending Tuesday Club. He was in hospital and he had cancer all over his skin. He said, "No one wants to look at me like this."

Suzie asked what it would take to get him out of that bed and into Tuesday Club. He told Suzie that only a belly dancer would. Suzie approached Sue Graham and the belly dancers offered to visit, and then organised it on a regular basis. Great entertainment. It wasn't long after, heading toward Christmas, that the patients had a morning decorating cut out Christmas trees with buttons, glitter and jewels. One Christmas tree looked like it had a bright blue evil eye right in the middle of it. When asked what it was, he responded that it was the jewel in the belly dancer's belly button!



Another patient had heart failure and he was attached to an oxygen concentrator. He said, "If we go out, where would we go and what would we do when we got there? Everyone stares". For him, the Tuesday Club became an absolute sanctuary. When he was too unwell to attend, he insisted his wife came because he knew how well loved and supported she was there. She would be able to have a bit of her own respite and get involved in the activities.

A volunteer massage therapist, Paula Lawson, would offer massage therapy to those patients and caregivers who attended Tuesday Club, and another therapist used the room on a Tuesday afternoon to help relieve stress in caregivers and volunteers. The relaxation therapy proved important for some patients who suffered acute anxiety or panic attacks, or had problems sleeping.

In later years Merril Ridley would call in and do a podiatry session on a Tuesday for patients who lived in Turangi or further out and Josie, who managed the Bereavement and Kowhai Group, was there for counselling. It was also a lovely time to introduce visitors to patients. It became a focal point for patients.

An extension of another room was made at Hospice House to assist with space but very soon the Tuesday Club outgrew that area too. The popularity of Tuesday Club was one of the main drivers to look for a new venue for Hospice House.

On Paula's resignation from the massage team, Pania Stewart was welcomed on board. With her extensive experience in many forms of massage she was an asset to the team. Likewise, Fiona MacDougal, with her background in Occupational Therapy, was ideal to take over from Dianne Maxwell.

"Mary Griffin was instrumental in purchasing the beautiful electric bed for massage. We used to have public forums anyone could attend, and we spoke to them about Hospice and the services we offered. Mary came up to me after one of these meetings and said that she loved the sound of the massage service. "If I was ill, massage is something I would love." She asked me what that service needed. I showed her the massage room and she said, "I could never get on that table." She asked me how much an electric bed would cost, and I replied, "Mary, far too much." She said, "I don't care. I want everybody to be able to access this service." Mary paid for the bed and all of the supplies in the ensuing years."

Suzie Kuper

It was suggested that the budget for food for the Tuesday Club be increased to take the financial burden off the volunteers who had been augmenting the budget with donations of food on a regular basis. It was agreed that food costs should be monitored, and a pantry of staple items would be established for volunteers to draw from. Following this, Leanne Vlaanderen met with Andrew Milne, the General Manager of Suncourt Hotel, who not only offered to fund the Tuesday Club catering, but also wanted to be a sponsor for the 2015 Creative Catwalk. \$8,000 had already been allocated to the Tuesday Club and a further \$2,000 was set aside for the naming rights to one of the categories at the next Creative Catwalk.

"We didn't worry about how many people attended Tuesday Club or restricting numbers. We would always find another chair and squeeze everybody in. Sue Treadwell was hugely instrumental in making sure the freezers were incredibly well-stocked. That was her job for many years. She was in the background making sure everyone was looked after and she had another 20 to 30 baking volunteers on her list. She knew every one of them and what they were capable of too. We were blessed with incredibly good people. We only had to say what we needed, and it would happen."

Suzie Kuper

Ray Goddard is the dedicated volunteer who set up the library at Izard Hospice House. He has been involved as a companion at Tuesday Club for a long time. He meets and greets new people to Tuesday Club. He gardens, grew tomatoes up at Sunset Street and then established the library for the patients.

Tuesday Club continues to provide a social environment where patients, family/whānau members and friends are warmly welcomed. Friendships are quickly developed, providing support and encouragement for each other. Activities are varied and include musical entertainment, quiz sessions, reminiscence, outings, presentations, creative activities, and social games with the emphasis on enjoyment for all. The massage service is available throughout the morning and a wonderful two-course lunch is provided by our dedicated team of volunteers encouraging a time of sharing and companionship.



Making Christmas decorations



Volunteers, staff and patients celebrating St Patrick's Day

# Bereavement Programme and Kowhai Group

The provision of Hospice services, paid for by District Health Boards, was being revised to include a unit on loss and grief. Lake Taupo Hospice recognised there was a need to develop a formal loss and grief programme for spouses after the death of a partner. At that time, LTH was dependent upon the volunteer service provided by Elizabeth Harker's group, guided and assisted by Dermot Buchanan from Lakeland Loss and Grief, and they needed to consider a succession plan, as well as provide some financial recognition of his work and the costs he incurred in providing it.

In 2008, a small working group made up of David Maling, Suzie Kuper, Derm Buchanan and Maurice Gianotti, put together proposals for the Trust to consider. These proposals included establishing a programme for partners and spouses after the death of a partner, at an estimated annual cost of \$3,000, and to identify a person to work alongside Derm Buchanan to ensure there was a succession plan in place.

After the death of a patient, partners and spouses often faced considerable difficulty in rebuilding their lives, and to fill the gap left by no longer having to care for a terminally ill loved one. The difficulty was compounded by the tendency for previous social networks to fall into disarray because of the need to focus on the patient. Immediately after the patient died, the partner would be in most need of the support of friends and social networks, and those would need to be rebuilt. People often needed help to do it.

The Tuesday Club was not designed for bereaved people. A different programme was needed to which spouses could progress from the Tuesday activities programme. People could continue to have the choice of an individual counselling programme or attendance at the Bereavement Programme, or a mixture of both. For some years, Derm had provided a highly valued grief and loss support service to individuals and had also led group services. These services had been given to Hospice on an entirely voluntary basis.

The programme co-ordinator would be paid for an average of four hours a session and with further costs for guest speakers, materials and fees, would total approximately \$3,000 per year. In 2008, Jacky Gartner was appointed Grief and Loss manager to organise and run a suitable grief programme with Derm's assistance. One of her objectives was to set up the Kowhai Group, with the aim of helping people back into society.

Paula Lawson was chosen to replace Jacky Gartner in 2009 as Kowhai Group counsellor, with Jacky agreeing to stay to help Paula settle into the job. In 2012, Josie Harris was appointed to lead the Family Support Team, replacing Sheila Roberts.

Josie had been volunteering for Lake Taupo Hospice off and on from around 2000. In those days she would go out to homes and sit with patients who were dying. She did this for several years before taking on the new role. Josie was key to the counselling and social work services. She is a multi-talented person, originally a nurse, then social worker and counsellor, and then working in bereavement care.

The Bereavement Group have a monthly meeting where the care co-ordinators discuss specific patient cases with a team of volunteers who follow up with the families. Sometimes this follow up consists of just one phone call and sometimes telephone or home support is given over a few months to gradually get the spouse/partner to the stage where they would be happy to socialise. At that stage, the spouse/partner would be invited to Kowhai Group, which also meets once a month.

Many people would come to Kowhai Group for support. It is more of a social activity and education, rather than counselling. Josie started with a six-week programme to talk about loss and grief, what to expect and how to expect it, and to normalise death and dying. By listening she would find out what was happening in their lives and give them coping mechanisms.

One woman said that she found it very strange going into town after her husband's death. When he was alive, she would rush to town, get everything she needed and then rush back home for him. He has been dead for five months and she was still doing that. She now questioned this behaviour. "Why am I doing this when there is no need to?"

Some Kowhai Group members have difficulty with going out and coming back to an empty home. Suggestions and practical ideas can be made like leaving a small lamp on, the television going, or maybe just a radio. Just giving the bereaved skills on relaxation and mindfulness are helpful as they would still get stressed out. Things can trigger grief and stress like major milestones, birthdays and anniversaries.

One woman said that her husband always wanted to tour the South Island in their motor home but died before they were able to. Kowhai Group managed to get this lady to believe in her own abilities and she toured the South Island by herself, even though she was very anxious about taking a large motor home over on the ferry. When she came back to the group a month or two later, she was more confident and on hearing her story, others said that if she could do it then so could they.

For the Hospice team to come in at the beginning of the journey is paramount, as it can take a few months to build a relationship and trust. When the patient dies, it makes it easier for the carer to continue the relationship with Hospice.

Josie tries to work them through the process to when their loved one dies. She helps them work through anticipatory grief and loss for both the patient and the spouse. The patient might be losing their hair, or teeth, or job. They are all losses.

Trust and relationship need to be in place as the patient is dying. It is important that the patient and the family feel secure enough to answer personal questions such as where would you like to die, would you like to be buried or cremated, or who is your power of attorney. They need to feel they are important and special, and there is time and concern for them.

The Kaiawhina provides psychosocial care, grief and loss support to Turangi, Māori and Pacific Island whānau and bereavement support to family/whānau across the service. The role supports the Family Support Team Leader and works to provide cultural liaison to ensure the psychosocial, emotional and cultural needs of patient and whānau are met. Bereavement care is provided before and after the death of the patient and assists carers, family/whānau with their loss and grief.

The Bereavement Programme and Kowhai Group ensure that those family members left behind have adequate support and their integration back into the community is assisted. Twice a year a Memorial Service is hosted to which family and friends who have lost a loved one are invited. A beautiful remembrance.



### **District Nurses**

"Many years back, the Hospital Health Society provided rooms at the hospital for terminally ill patients. We used to have a nursery but as things changed, we could no longer care for children in the hospital. It was a large room with six beds, and with funding from the Hospital Health Society we converted it into two rooms complete with en-suites, with the idea that they could be used for terminal patients. The rooms were a bit bigger, more comfortable, with room for family and were quite private where they were situated.

In the early nineties, we had a system at the Taupo hospital where we made charts for the terminally ill patients with their drugs all recorded on their charts so they could come in at any time of the day or night without a doctor's referral. That worked really well. Patients came in a lot less often because they had the confidence that they could turn up at two in the morning, their drugs were all charted and they didn't need to try and get a GP out of bed. At this stage there was no hospice in Taupo and the hospital doctor would look after them."

Laurie Burdett

Laurie had been a trustee of Lake Taupo Hospice Trust right at the beginning. The Taupo Hospital, a small community hospital in those days, was very doubtful about Hospice at the early stage. GPs looked after their patients in the hospital and the hospital tried to provide a terminally ill service. Once they had a lovely little old lady who lived at the hospital for three months because she had nowhere else to go. It would be unheard of these days. Patients were kept a lot longer and were provided with a good service. So even though it wasn't the focused service that Hospice provided, it was a service that was already in existence. As times changed, the hospital became more restricted and more specialised, and the Hospice blossomed.

The Friends of Hospice had an excellent relationship with the Taupo Hospital. In the early days, the district nurses came under a different structure, so weren't employed by the Hospital. It was a totally separate service where the district nurses were firstly employed by the Waikato and then the Rotorua Health System. Taupo used to fall under the Waikato Health System and then changed to the Rotorua Health System, which was Crown Health Enterprise. Lakeland Health funded the district nurses via the Community Health Budget.

Palliative care patients were referred to the Community Health Service. When the patients were discharged from the hospital, they had only residential care or their own homes to go to, and the district nurses followed up with the palliative care in the community.

Judy Tunnicliffe was one of the district nurses and worked closely with the Friends of Hospice. She had done her training and had been a district nurse around the coast in Taranaki as they were farming there.

In August 1997, she asked that a letter be written to the Operations Manager of Lakeland Health notifying them of her position as the District Nurses' representative of the Friends of Hospice Committee. She would attend the meetings every month and present a report to inform the Committee what was going on from the nursing side and what the needs were for the patients, both regarding caregivers and equipment. Waikato Community Health Services provided some equipment but the Friends supplied the District Nurses with electric control beds and all the extra things like the sheep skin rugs, Spenco mattresses, things to prevent pressure areas like good cushions, elbow and heel protectors, shower stools, all of which made the patients more comfortable. Sometimes the District Nurses were able to purchase equipment for the patients from donations given to them by grateful families and money given in lieu of flowers. Judy kept an inventory of equipment they used and let the Friends know when equipment needed fixing or mattresses needed cleaning.



Judy Tunnicliffe with equipment provided by the Friends

By attending meetings Judy was able to keep up the contact with the Friends Committee as they didn't have any building or formal structure in those early days. District nurses didn't just have palliative patients. They had all the other parts of the district nursing job to do so their days were very busy, and Judy saw the need to have an input at the Friends meetings.

In 2000, Ros Swainson, Suzanne McCleary and Rachel Dykes were all district nurses and provided a cohesive working relationship with the volunteer care givers.

As time progressed Suzie Kuper was employed and, whilst she didn't really have any authority over the district nurses, they worked closely with her. At that stage, the nursing started to evolve to 24/7 care. Janet Gainsford took on a co-ordinator role.

"Well, what a moment. On arrival to visit Mr X, a huge smile greeted me, he leapt out of his lazyboy chair and met me at the door, which was very significant. "With a delightful smile and a twinkle in his eye, he said "That bed!". (Yes, the one that was half size when delivered, the two very helpful men had to deliver and alter parts for over two days.) "I have had the best sleep ever. I looked at the time as I awoke and could not believe it was 05.30, and no pain!" Then, as his wife has back pain, "I put the bed to full height for her to make it". She smiled and said that she had made the 'high' bed with no effort at all. The challenge is to put into words the significance of this episode for this couple. They have had major challenges with symptoms and accepting this equipment was also an obstacle to overcome. Yes, we at Hospice have really helped."

Janet Gainsford - April 2011.

"This week I met a new patient, a tiny Maori lady who lives some distance away in the home of her Whanau and which she rebuilt herself over the last 16 years. She has resisted referral to our service due to fear of further losing her independence, a story familiar to many. She had several over-riding issues, pain, and inability to sleep amongst these. My initial visit felt relaxed, we sat and identified issues, listened and then with reasons and explanation, I suggested a regime which included medications and equipment to improve her quality of life. The equipment included a bed with a pressure mattress, and a wheelchair which were delivered the next day by a wonderful Taupo Lions Club member. The following week I phoned, noting a stronger tone of voice as she explained, "I am much stronger and have the pain well-controlled now that I am taking regular medications as prescribed. Yesterday I ate three good meals and the food is going down to my stomach. This morning I ate a huge breakfast of steak and spaghetti. The bed is a dream. I am sleeping half-sitting up and having a proper rest., My daughter wants to take me for a walk by the lake in the wheelchair but it is too cold at the moment, but I am almost strong enough now." This again is why we are all here."

*Janet Gainsford – June 2011* 

Hospice Community Nurses provided 24/7 comprehensive patient and family/whānau nursing assessments, co-ordinated the care provided by all palliative service providers, provided compassionate patient and family/whānau focused nursing care, assisted family/whānau with the knowledge and support needed to contribute to the care for their dying family member, acted as resource people for other health professionals for palliative care problems and advocated on behalf of the patient and family/whānau whenever necessary.

Three nurses were rostered each day Monday to Friday, one nurse to cover from the Napier –Taupo Rd south to Turangi and Northern National Park, one nurse in the central town area, and one nurse to cover from the Control Gates bridge through the north western suburbs, Acacia Bay, Kinloch and north to the Mihi bridge. Three days per fortnight, four nurses were rostered on to keep pace with new patients, urgent hospital discharges, along with increasing documentation, core competency and education requirements.

Initially night nursing was accessible through the Cancer Society. Later the DHB contract enabled 10 nights for a patient, but very few would have used the 10 nights. The nurses only used it if a family needed a break. It was a good service when someone was really needed and perhaps prevented the patient from needing to go into residential care. Just a stop gap to give someone a night's sleep and abdicate responsibility for that patient for those hours. The District Nurses used to teach the family to do the extra injections through the pump lines if necessary and were available for those night nurses if they had any concerns.

As part of the contracted service with Lakes District Health Board in the transition of the domiciliary palliative care contract in 2012, night care for approximately seven nights for end of life care support at home was to be provided by Lake Taupo Hospice. The \$5,000 per year from Lakes DHB to fund the service was included in the bulk funding. The service was provided by qualified Home Support Workers contracted to LTH.

A 24/7 after hours on call service was provided by LTH nurses. The on-call nurse was available for urgent after-hours advice and support and endeavoured to deal with issues by telephone wherever possible. If telephone intervention was not possible an after-hours visit would be conducted if appropriate. Nurses were paid for being on call and call outs, but not for telephone intervention. Nurses were expected to attend work the next day unless the interrupted sleep had been significant. On weekends and public holidays, a nurse was rostered on for patients newly discharged from hospital, or patients with high and complex needs. This nurse was also on call overnight at the weekends.

Changes to treatment over the years and palliative care offers more treatment now. A referred patient who is in the palliative care stage of their illness may start on chemotherapy or immunotherapy and then stabilise and live a lot longer.

"We have a lot of patients who are getting good treatment and have stabilised. That also happens with our respiratory patients. They are referred to us when they are really ill and then stabilise with treatment. With things being managed better, those people are living a better quality of life, which gives other patients hope. People are living longer as treatments improve. The population has grown significantly in Taupo and it isn't just the older generation who require palliative care. It is going to be interesting to see how things are going to operate and how we are going to get funding for the future."

# **Living Every Moment**

Taupo Hospice was the first hospice in New Zealand to be recognised as community-based, using caregivers and training them to look after people at home rather than having inpatient beds which it could not support. Advice was sought from the Tindall Foundation regarding funding, and their response was to say that a population of a town the size of Taupo at that time (30,000) could only really afford to raise a maximum of \$50,000 per year. Therefore, it made sense to work within this parameter and get money from outside sources through charitable trusts as well as through fund-raising within the community.

At the AGM of the Friends in April, it was revealed that they had raised \$83,870.59 for the year ending 31<sup>st</sup> March 2007. This was a fantastic result. It was also agreed that the Friends' constitution should be looked at and, after consultation and advice, be updated. More money rolled in, with a successful lecture by Gareth Morgan netting \$5,416 and an equal amount being donated by the Gareth Morgan Trust.

Negotiations with the Lakes District Health Board were proceeding over Hospice's share of a contribution to a palliative care physician. It was also decided to write to the Lakes District Health Board enquiring about the reason for and expressing disappointment at the lack of consultation over recent cuts to healthcare for the disabled and elderly.

The Trust held ongoing discussions about staff requirements and remuneration to ensure the smooth running of Hospice. They understood that volunteers such as Derm Buchanan, were putting in large amounts of time and energy into doing valuable unpaid work.

At the Trust AGM on 18<sup>th</sup> of June, Chairman David Maling reported that the Trust had prepared a Business Plan, agreed to adopt new measures in palliative care and lobbied for access to specialist treatments for patients. By July, a new Trust Deed provided that the Trustees of the Board would be appointed for a term of three years and retire by rotation. Ratana Wall was re-appointed by the Te Nohanga Kotahitanga o Tūwharetoa Health Charitable Trust, and David Maling's appointment was approved by Dr Peter Battersby, Laurie Burdett, Wha Mclean, Chris Carl and Ratana Wall.

Suzie, the Palliative Care Co-ordinator, continued to link palliative care with new patients, doctors and district nurses. She needed more active rehabilitation equipment to assist in coping with the increase in patients and it was agreed to approach a charitable trust with a view to funding these purchases.

Sadly, Leonie Pritchard left her role with the Lakes District Health Board. She had been a great supporter of Hospice and an advocate of the belief that it was the centre of Palliative Care co-ordination in the community. At the end of 2007, the number of Friends stood at a healthy 419.

It was this year that the Lake Taupo Hospice Trust became a full member of Hospice New Zealand and adopted the new logo as recommended by Hospice New Zealand.

In May 2008, Laurie Burdett stepped down from the Trust and was warmly thanked for her many years of supportive contribution to the Hospice.

At the Friends of Hospice AGM, Hugh Treadwell reported on the successful Antiques Roadshow fundraiser which had been held at the Yacht Club in April, with David Holroyd (china), Brian Apps (silver) and Mary Dixon manning the various tables. With over 160

entries examined, the net takings were \$1,735.



Daphne Emery helps Alison Courtier prepare for the Mizino Half Marathon

The film *Cultic* had earlier brought in \$1,100, and Pak 'n Save had raised \$5,660 with the "add a dollar" appeal. The excellent garage sales continued to bring in money too. Four thousand dollars was raised by Team Taupo at the Mizuno Half Marathon, held over the first weekend of August. \$1,000 of this was from sponsorship for patient Alison Courtier who completed the course in under four hours.

Then, once again, there was the wonderful Pauline de Lira's Cabaret show which netted a further \$2,297. The Contact Energy golf tournament was a huge success and a very generous donation of \$21,500 was received

by LTH. Together with further donations from the International Motocross Rally, Karin Corin's Christmas "Light up your Home" and the Christmas Candle Appeal, the generosity of the people of Taupo towards their hospice was quite overwhelming.

There was an increase in the net assets for the year of \$100,000 and \$75,000 in cash reserves, though the Lakes DHB expenses had increased to 52%.

In the meantime, attention to Hospice House in Sunset Street was required with a water pipe break needing repairs. Plans for improvements were also being discussed, as larger kitchen and reception areas were needed for the burgeoning numbers of people coming through. Towards the end of the year these renovations got the go ahead with funding from Bay Trust for \$90,000. An interest-free loan of \$20,000 repayable over five years was agreed to, with the balance coming from cash reserves. It was decided that plans were to be put to five interested builders for quotes to complete the renovations. Lake Taupo Hospice Building Fund was created to keep a second account for building capital and to clarify the financial position when applying for charitable funds.

Business was all systems go at the start of 2009 and by February the new garage in Puriri Street was complete. BNZ staff came to the party, painted and put up shelves in the garage. Sales, which had been disrupted by the building works, began again.

Alison Bowman had been to a Hospice NZ fundraising workshop in Wellington and reported back on the need to set up a website for Hospice. She spoke about the benefits of a "Bequest Programme" and "Time to Remember" occasions. By April, she was sending out email bulletins to supporters and volunteers to publicise all events. It was then agreed that a web site be set up for the Trust.

The renovations to Hospice House continued to go well, with excellent work being done by both builders and sub-contractors. Volunteers helped where possible, with everyone putting huge amounts of time and effort towards its completion. With the overseeing of the house done by John Wallace and the gardens by Stuart Williams, everything moved along smoothly, and the renovations were completed in May 2009. Hospice House provided a wonderful, friendly venue for the increasing number of patients and services, plus a pleasant outdoor venue for the art group.

Opening Day Celebrations on 8<sup>th</sup> of July started at 8.30am with a blessing of the new house extensions performed jointly by Derm Buchanan, the LTH Chaplin, and Mataara Wall of Waitahanui. This was followed by coffee and muffins and then an Open House morning where a stream of visitors walked through the house, many staying for a cup of tea and a chat.

Later that day a well-attended Volunteer Appreciation Party was held, after which there was an opportunity for those attending to look at the new facilities. All the volunteers had been sent "appreciation dollars" in advance and with the assistance of the local business community who donated prizes, and auctioneer Dave Wallace from Harveys Real Estate, they spent this money bidding for blind lots. Prizes from local companies included games of golf, beauty therapies, thermal pool passes and a range of gifts. A great time was had by all and the auctioneer was heard to comment that he wished all his auctions enjoyed such spirited bidding!

Among the invited dignitaries for the formal opening that evening was the Mayor Rick Cooper, the Hon. Georgina Te Heu Heu, Ratana Wall, Barry Keehan, Lyall Thurston and Vanessa Russell. Chairman David Maling thanked the builder Warren Cholmondeley-Smith and his sub-contractors, designer Doug Johnston and John Wallace, as well as those who had donated materials and financially helped the dream become reality. He also paid tribute to the volunteers, health providers and the community, before asking the Taupo electorate's Member for Parliament, Louise Upston, to officially open the building.



Local MP Louise Upston with David Maling at the opening of the extensions to Hospice House

The Living Every Moment campaign had been launched in May as part of the National Awareness Week with articles in newspapers, magazines and other media aimed at raising awareness of Hospice work. Part of this campaign was the web-based concept of sending messages to friends, family and business colleagues. A new letterhead using the kowhai branding was printed.

At the 2009 AGM Hugh Treadwell was appointed Chairman of the Friends of Hospice in place of Chris Carl, who was thanked for his leadership and hard work. On the financial side, funds continued to roll in throughout the year, with a concert by the Topp Twins at the Great Lake Centre in May, the Mizuno Half Marathon in August and a successful Lake Taupo Bridge fundraising tournament all making contributions. Pauline de Lira's Cabaret again donated over \$2,000 from her annual show, and this year the money was used to purchase additional outdoor furniture. The Cruising for a Cause family fundraising event proved to be popular and raised \$3,592. Together with Huka Falls Jet's \$4,470 and a donation from Taupo Lions of \$2,000, this made it a most successful fundraiser. In addition to all of this, a very generous donation of \$35,312 was received from Baytrust.

Amanda Mole was appointed Patient Care Co-ordinator, taking over on the resignation of Ruth Sneider. Her job description was changed from Palliative Care Co-ordinator to Patient Care Co-ordinator, thus making her title more readily understood by families using the service.

July saw a great result from a patient survey which showed a near 100% satisfaction response. David Maling, Trust Chairman, congratulated Suzie, Alison and Terri for the quality of their service and for a well-run palliative care system which was recognised nationally.

Jo Tinworth offered to train two new Turangi biography volunteers, so Hospice was now able to provide this service for the southern part of Lake Taupo. She and Alison developed some procedures and new permission forms for the biography group. It was also agreed to have biographer support group meetings approximately three times a year.

As part of Business Network International's (BNI) 10<sup>th</sup> birthday celebrations, their Head Office donated \$21,000 to Hospice NZ to distribute amongst the branches. The Lake Taupo Hospice share was \$875 and local BNI members assisted with painting the fence and fixing some window security stays to Hospice House windows.

Finally, having had a visit from Minister of Health, Tony Ryall, earlier in the year, it was announced in November that there would be new Government funding for all hospices, with approximately \$92,000 being allocated to LTH. It was acknowledged by everyone that John Wallace, the Treasurer, had been greatly instrumental in ensuring such a large amount for the area.

### **Strategic Plans**

At the start of 2010, a discussion was held about placing Night Nurses, who worked on an infrequent basis, on employment contracts. Concern was expressed about where the responsibility would lie if an accident happened when they were on duty. The contracted personnel were presenting the face of Hospice and, in the eyes of the end user, were Hospice.

An appointed subcommittee, in association with Suzie, had been looking at a suitable management structure to carry Lake Taupo Hospice forward for the next five years. They recommended a new position of Clinical Nurse Educator to handle the Liverpool Care Pathway, Age Residential Care, relief Palliative care co-ordination and community education. This would require a qualified nurse for approximately three days a week.

A report on PalCare, the web based palliative care administration system, had been received from Waipuna Hospice. A cost of \$9,000 was identified as Taupo Hospice's share of the software and \$10,000 would be put aside for the first year's subscription. The financial situation, resources, future expectations, and estimated budget for May 2009, showed a jump in income, both earned and donated, to date. While it was still necessary to raise \$35,000 per year, this was considerably helped by garage sales and donations drawing from the community.

The Taupo Friends of Hospice suggested that it would be a good idea to maintain the hospice profile in a modest fashion, fundraise with a purpose in mind, e.g. a piece of equipment, but continue with routine events such as Card Day, Half Marathon and Christmas Candles and try to target the younger set. They were also keen to give greater support to the garage sale volunteers as it continued to grow at an excellent rate. There were ongoing attendances at conferences by staff and Suzie had her first slot on Tūwharetoa Radio with Ratana Wall.

Two new services with huge benefits were offered to the patients and their families. As a result of some additional funding from the Ministry of Health, Lake Taupo Hospice was now going to have a Palliative Care Specialist Doctor visit Taupo once a month and hold a clinic at the Hospice. The primary benefit of this was that patients would not have to travel out of town for consultations. The second service was a Carers' Programme designed to help family and friends care for loved ones at home. It would include practical information about things such as transfers and mouth cares (oral patient care at the end of life), as well as emotional support.

In April Wally Niederer, farmer and former vet to the New Zealand Olympic Equestrian team, hosted a group of Lake Taupo Hospice supporters at his farm Harakeke. This "Pleasant Pheasant Frolic" outing, complete with clay pigeons and Wally's wonderful reflections on his Olympics involvement, included the wonderful assistance of Grant and Nigel and proved to be a well organised and most enjoyable day out for everyone attending.

The great "Celebration and Art Auction" evening at Danske Mobler in May raised \$3,445.50 which was a wonderful effort. The Bridge and Mah-jong day in July raised approximately \$1,000 and August's book talk by author Da'Vella Gore at Kinloch brought in \$1,180. With the Mizzuno Half Marathon delivering \$2,000 and good bereavement donations also received, the fundraising year started well. The Garage Sale team cracked the \$30,000 mark for annual turnover which was an amazing milestone!

The death of John Wallace in May came as a sad shock to everyone involved with Taupo Hospice. John's contribution to the workings of the hospice, together with his direct and willing loyalty, would be sadly missed. Even though his role was a financial one, he never lost focus on the important aspect of hospice – the patients. In a moving ceremony attended by Sue Wallace, a memorial plaque to John was unveiled that November.



At the June 2010 AGM, Chairman David Maling explained the funding position following recommendations from the Ministry

of Health and Lakes District Health Board, for certain criteria to be met for the hospice to qualify for funding. He also spoke of the success brought by the visiting palliative care specialist and the continuing education of the LCP system which would be carried out by the newest nurse educator.

Then, as part of an extensive report to the Lakes Trust District Health Board covering the 12 months from July 2009 to June 2010, David listed the wide range of services offered by Hospice, the importance that was placed on top quality staff and the emphasis given to their continuing education. He spoke of the very successful combined culture of inclusiveness, openness and support nurtured by Hospice, which was evidenced by the endorsement of the community and patient/caregiver audits.

The Hospice's deliberate choice not to have inpatient beds was working exceptionally well and was meeting the natural human response for people to care for their loved ones with timely access to quality palliative care services that were culturally appropriate and provided for in a co-ordinated way. This also had the benefit of integrating the hospice into the community.

A list of services provided by the volunteers showed an astonishing range of unpaid jobs.

- time out for families/carers
- companionship
- shopping
- gardening
- lawn mowing
- transport assistance
- end of life presence and support home, hospital and residential care
- Tuesday Day Stay Club assistance
- massage (Tuesdays and at home)
- painters/art and craft group
- meditation/relaxation classes
- podiatry
- baking/meals
- hairdressing
- biography
- bereavement support
- firewood
- equipment delivery and collection
- fundraising and Garage Sales

The addition of night care staffing to Hospice meant that sufficient funding for the nurses' salaries needed to be guaranteed and there was concern as to whether this was being taken into account with changes to the contract with Lakes DHB. In addition, further monies would be required for the introduction of Version 12 of the Liverpool Care Pathway. A letter written to Vanessa Russell of the Lakes DHB at the end of July asked for clarification and further dialogue on these and other matters in order for the partnership between the two entities to remain harmonious.

Denise McKay was appointed as Lake Taupo Hospice treasurer on a contract basis and after nearly five years of sterling service, Wah McLean resigned from the Trust. Diane Maxwell joined Tuesday Club as the Day Stay Co-ordinator, Janine Colpman-King was appointed to the new position of Clinical Nurse Educator and Janet Gainsford accepted the role of Patient Care Co-ordinator. Suzie Kuper now had the title of Clinical Nurse Leader.

In August, the Garage Sales Team was nominated for the Trust Power Community Awards. The team had had an exceptional year showing a huge increase in profit and it was a great opportunity to promote this fundraising activity. A member of the public also nominated the Tuesday Club team so there were two entries! Although Hospice received no award that year, the volunteers were acknowledged and sincerely thanked for all their contributions to the community.

September saw the long-awaited ETA road opened. On its opening day funds were raised for various community groups, including Lake Taupo Hospice. The mayor, Rick Cooper also did his bit to raise funds by allowing himself to be put 'in the stocks.'



Freemasons NZ presented Taupo Hospice with two digital recording devices for the biographers and Strettons decided not to hold a Christmas function for their clients that year, donating \$5,000 to Taupo Hospice instead.

Having recently attended a Fundraising Workshop in Auckland in October, Alison recommended that a subcommittee be formed with the aim of assisting the Friends to take a new direction. This would be chaired by Bret Butler who had been newly appointed to the Trust. Early in 2011, Bret outlined his plans for co-ordinating areas of fundraising and providing a framework which could be targeted. He had listed all Charitable Trust funds and Business funds available for Hospice to apply for. This was separate to the Friends activities.

At Hospice House a heat pump was now in place in the kitchen area and new shelves and cupboards were installed for hallway storage. Due to ongoing problems with parking outside the house, a meeting was arranged with the CEO of the Taupo District Council to discuss angle parking outside. It was also decided that staff would park at Puriri Street whenever possible.

The application made to Transpower for funding for a complete set of equipment for Hospice for the Wairakei-Mangakino area was successful and \$23,330 had been granted. Finally, the Christmas Candle Appeal was run once again and as the year drew to a close, garage sales figures showed that \$48,000 had been made for the year. This was a huge achievement and a great credit to the team.

The Liverpool Care Pathway was progressing very positively. By February, planning for a transition to LCP Version 12 with education sessions with General Practitioners, Aged Care Facilities and Ward 2 at Taupo Hospital had been organised and an inaugural LCP Resource Nurses Group had been set up.

Suzie had also been involved with developing the PalCare system. This was a sophisticated satellite operation which would provide Hospice with immediate details of a patient's medical background and thus save valuable time on research. The Wendy and John Norwood Charitable Trust had come on board to assist with the initial funding and was continuing to do so in a significant way.

Early in the year Alison Bowman reported that there had been a small flurry of people interested in volunteering, and orientation sessions had been arranged for them. Among the newcomers was a beauty therapist, who was a useful addition to the team, and two more volunteers for the Tuesday Club cooking team. Alison had also been in contact with other hospice volunteer managers to discuss how they recruited, trained and managed teams for their shops. With \$1,000 being taken in just one week in garage sales in Puriri Street, the shop opening was becoming closer.

Alison was also working on a Bequest programme, while Denise assisted by compiling a suitable brochure. At the Hospice Trust meeting held on the 15<sup>th</sup> of March, it was agreed that a separate account for bequests would be opened and called the Lake Taupo Hospice Foundation, Capital or Endowment Fund Account

There had been a confirmed grant from NZ Lotteries towards Alison's wages and a couple of smaller grants, which signified just how valuable the money raised by the Friends was to Hospice.

Lake Taupo Hospice strategic planning was underway, and input from staff, Trust and community stakeholders was all taken into consideration. The Mission/purpose of the hospice had been refined to 'Lake Taupo Hospice strives to be a patient and family/whānau focused centre of professional excellence, for providing specialist palliative care to all those with active life limiting illness. We recognise diversity and act professionally with compassion. We work in partnership with our communities and other health service providers to ensure that our patients may live every moment and die well supported with dignity in a place of their choice.'

With challenges such as increasing life expectancy, an ageing population with higher needs, longer palliative survival, changing family structures and shifting patterns of work and retirement, a small subcommittee was set up to produce a document for the Trustees to discuss and amend in time for the start of the new financial year in July. Some suggested goals were to:

- maintain and strengthen the position of Taupo Hospice as the lead specialist palliative care provider for the southern half of the Lakes DHB
- strive to ensure that all patients and their families were cared for with compassion by well-educated team members
- affirm personnel as Hospice's most valuable resource
- maintain the LTHT strong financial position to sustain growth and developments for the future benefit of patients
- promote effective communications and positive relationships with all service providers and the communities at local and national levels
- maintain the most effective management and operating structures to support our mission and vision
- establish and maintain realistic standards and expectations, developing a set of policies, procedures and publications relating to all facets of Hospice life
- provide and maintain appropriate facilities.

At the 2011 Friends AGM, Chairman Hugh Treadwell reported that they had not held a major fundraising function during their financial year as they were aware of the focus on contributions countrywide to the Christchurch earthquake. He thanked the many people who had helped in various ways with assistance, organisation and promotions for various events. Stuart Williams, the fetch and delivery man, and David Jalfon, who used his skills with Trade Me for marketing the garage sales, were particularly mentioned, as was the work of the garage sales team who had done such an amazing job over the years, sometimes in very difficult conditions.

In a written Friends' report, it was noted that there would be an expected shortfall for the year of approximately \$150,000 between funding received from Lakes DHB and expected expenditure of the Lake Taupo Hospice Trust. During the previous year, \$45,000 had been raised from garage sales, with a further \$4,200 coming from Trade Me. It was hoped that with the new shop, those figures would be exceeded. Over \$2,400 was raised from a Ladies Nine Hole Golf Tournament and Craters of the Moon Trust's donations of about \$50,000 over the past ten years was acknowledged by Suzie Kuper in the Taupo Weekender.



Derm Buchanan at his farewell

Hospice Trust Chairman, David Maling reported that Derm Buchanan would be leaving Taupo for Tauranga in September. He had been an absolute stalwart for the Hospice, filling many roles over a number of years, as well being its Pastoral Minister.

The findings of the August audit were very satisfactory. These audits were done to assess compliance with Lakes DHB and identify strengths and areas for future development in service delivery, management and administration. David's July Report noted that the contract with Lakes DHB had been drawn up for two years, instead of a single year as had been

done previously. The Government had agreed that funding would stay the same until 2013 and Government funding for the year would be \$318,549, with a further \$13,959 being granted from allocated funding.

Later that year, Brian Bockett presented a report to Lake Taupo Hospice Trust which looked at the advantages and disadvantages of setting up a Charitable Foundation to attract and hold funds to be invested for the benefit of the Hospice. Many other hospices had formed Foundations that were proving extremely successful. Essentially the Foundations were designed as a "focussed" means of raising investment capital, managing investments and hospice assets, in an entirely separate entity from their hospice operations. He also suggested that a more professional fundraising co-ordinator be considered to compete with other organisations, many of which employed professional fundraisers.

As the year ended Chairman of the Friends of Hospice, Hugh Treadwell, reported that the hospice boxing star, Garth Beker, had won his bout in the "King of the Ring" fundraiser and raised \$10,000 for the cause. The Christmas Candle tree had been organised by Chris Carl, and Strettons had once again donated \$5,000 in lieu of their Christmas party. Both Hugh and David Maling made a point of thanking everyone individually for their many and varied contributions to Taupo Hospice.



Wayne Morris and David Wickham of Strettons hand a \$5000 Christmas cheque to Hugh Treadwell.

David said that he was aware of everyone's incredibly hard work and the demands that were made on their services. He warned that a clear signal had been put out by the Government that future funding would be reduced, so ever more careful use of resources would be necessary in the coming year.

# **Hospice Shop**

The enormous success of the Puriri Street Garage Sales meant that it wasn't long before storage became tight there too. Extensive work done throughout the country had shown that hospice shops were a great source of revenue and there were high hopes that a shop could be an excellent ongoing source of income for Taupo Hospice too. The time had come for a search for premises for one, and Erin Jones took on the task. It wasn't an easy one, but eventually, with support from Glynn Pointon, space was found in Totora Street.

Barry Keehan, Maurice Gianotti and Erin met with Glynn to sort out lease issues for the new shop in 2011 and it was agreed by the Trustees that an application would be made to the Sutherland Trust for \$50,000 to cover the many setup costs.

By April progress was being made, with the floor poured and builders finishing the main side wall. Estimates had been received for security and a telephone and installation costs for Glynn's recycled air conditioning units had been sought from Stu Groombridge. Signage was being looked at too, and volunteer co-ordinator Alison Bowman had already received 14 names for staff without any advertising or recruiting.

In July, Donna Ferrall was selected from a high calibre list of applicants to be manager of the shop. With six weeks to go until opening day she started planning, training and organising volunteers, setting up procedures and focussing on the layout. Erin Jones enlisted the services of Alan Payne and he and Alison Bowman used their contacts to organise voluntary painters to paint the shop, while Liz Connell and David Maling busied themselves painting shelves. Trust members, including Erin, Jo and David Maling, spent countless hours assisting with the sorting and pricing of stock in the shop. With the shop



Donna Farrell and David Maling at the Hospice Shop opening

opening date set for August, goods were transferred from Puriri Street to the new premises. Added space for storage was eased by two additional garages and volunteers worked tirelessly to ensure that everything was ready on time. Donna met with the wonderful people who had been running the sales in Puriri Street, and in spite of some initial misgivings, they agreed to join the staff at the new shop. Following the final garage sale on the 20<sup>th</sup> of July, a special lunch was held for those volunteers who had been involved with Puriri Street since its beginnings. Happily, some of them are still volunteering at the Totara Street Hospice Shop to this day!

Everyone agreed that the opening of the shop was a great success, with David Maling saying that there was a feeling of "family" in the Totara Street shopping precinct. The Volunteer Appreciation Party held in the new shop saw BNI members serving, clearing food and tidying up. The Hospice Shop was truly underway and initial customer reaction was very positive.

By September 2011, Donna had 70 shop volunteers on her books. She had a great core group who worked well together. Her aim was to continue taking on volunteers to cover sickness and holidays so that they were able to have six people each shift, a total of 60 volunteers a week. Donna planned to train up some potential team leaders to run the shop each shift.

Hospice NZ ran a campaign called "Give it Up" for Hospice in 2011. It had two phases. The first phase called on the public to donate a designer piece from their wardrobe to Hospice. Special tags were placed on these items and they were displayed in the shop. Phase Two targeted the public, mainly the younger generation, to purchase designer items and put together an outfit. A photo of them wearing the outfit, purchased from the Hospice Shop, would be put on the Hospice website and people could vote for the best outfit. The person with the most votes won tickets and backstage passes to the Gin Wigmore concert.

By December average takings per day were \$1,000, with enormous amounts of donated goods being received daily. In addition, a garage sale held on the 3<sup>rd</sup> of December in one of Glynn Pointon's spare shops raised a further \$3,800. Donna had been working at a furious pace, and on the 2<sup>rd</sup> of the month, Susie White was appointed as her assistant manager to ease her load. Suzie White coped very well as Donna's right hand and Donna felt confident about leaving the shop when Suzie was there.

Although they never thought that they would outgrow it, within a very short space of time the shop had become too cramped, so Donna went to the Board of Trustees to say that a bigger space was needed. There was a location across the road which the Board thought would be too big, but she convinced them that it would be the right place. "I knew that we'd fill it in time and although the rental was higher, so the income would be." It was laid out in a series of "rooms" which she was convinced would be great for display purposes. A far wider range of goods could also be sold there. The Trust approved the subcommittee recommendation and the move took place early the following February.

There was no money for new carpets or paint for the new shop, but that didn't matter. More volunteers were found, and at one time there were 125 of them, working in rosters with team leaders. "They were a great bunch" said Donna, who made sure that they were kept happy by bringing in her own home baking and staying late to tidy up to ensure that everything was in the right place and spotless for the morning starts.

Sales were already about \$32,000 ahead of the same period the previous year and in addition Donna had run a Garage Sale in the old shop to move some of the goods.

A couple who were a tremendous support were Erin and Trevor Jones. Erin was on the Trust and was a terrific trustee. She was responsible for the garage sales and then instrumental in the transition to the Hospice Shop. Erin knew the Pointons well and instigated the shop at Totara Park. Because of her business background, she and Trevor were helpful in showing Hospice the way forward and how to engage and involve some of the business leaders around the district. Trevor and Erin gifted Hospice the first horse float which was the size of vehicle needed to transport the beds. The horse truck kept the equipment clean and dry, and it was easy to roll things off and onto the truck. John Crystal and Stuart Williams picked up garage sale equipment with it and delivered equipment to patients. Over the years, Trevor and Erin gifted the transport vans to Hospice, made significant donations along the way and were involved in so many things.

Neil Ladbrook was another key person involved and over the years the Ladbrooks have been incredibly generous to Hospice. Neil helped to establish the transport of beds through the Lions when Lake Taupo Hospice was in Sunset Street.

In 2012, Bob Glover, a volunteer, spent eight weeks of theory and practical training George, another volunteer, and Donna to carry out appliance testing on donated second-hand appliances for the shop. Appliance testing was a requirement of NZ Safety Standards, so Hospice felt that they needed to be proactive in ensuring that they complied with the standard and purchased a portable testing machine.

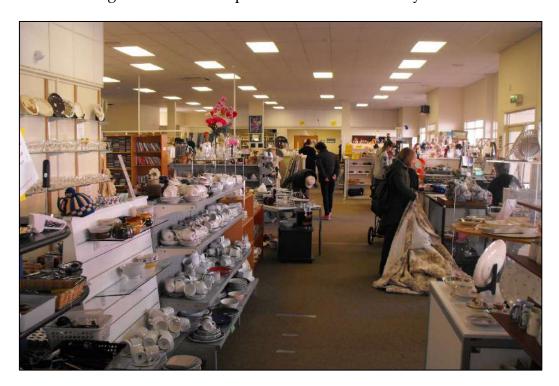
Attempts to source a second-hand hoist for the van were made through Trade Me. These were unsuccessful, and after discussion it was moved by the board "That the Trust purchase a new Gentle Giant lifter for no more than \$8,857.50 plus GST." After a Health and Safety assessment, they realised the Gentle Giant was not the best option from a workplace safety point of view. The main concern was that volunteers were holding onto and balancing furniture as it was being lifted. It was then proposed that a lift be installed which remained outside the van as it had a longer platform.

The outcome was that a tail lift for the fitted price of \$9,100 plus GST was approved by the Trust for a wheelchair hoist. This conformed to the recommendation from the assessor, and in May 2013, the tail-lift was installed in the shop van, ensuring that the men transporting the heavy goods for the shop were very happy indeed.

Although daily takings were increasing and volumes of stock were being received, some of this was unusable rubbish and caused excessive fees at the tip. There was no space left in the shop for storage and there were concerns about OSH and safely issues. The shop van needed maintenance. It had done around 132,000 kms and more than one person drove the van. Informal discussions were had about purchasing a second van. It would take the pressure off the existing van's usage and it would be easier to co-ordinate pick-up and deliveries.

Shop takings had by now reached a very pleasing \$1,600 per week and a full-time manager was needed to cope with the volume of work. It was time for Donna to step down from what she considered to be her most rewarding job ever.

In June 2013 Wayne Cooper took on the position. He had had extensive experience in retail and warehouse management, and in addition, had worked as a funeral director, so he had a great understanding of the work Hospice did in the community.



Inside Lake Taupo Hospice Shop

Discussions were already underway about opening a Turangi Hospice Shop and Wayne took over that planning. By October 2013 initial planning was complete, a building had been identified and budgets were prepared. Negotiations were held for a twelve-month lease for the property, with a six-month 'out' clause. Wayne would seek the owner's opinion regarding installing a ceiling to make the building warmer in winter. Initially the Turangi Hospice Shop would only open three days a week. New carpet was laid and \$340 spent on materials to build clothing bins.

The shop was opened on December the 13<sup>th</sup>, by Mayor David Trewavis and Ned Wikaira performed the blessing. Wayne thanked his staff, particularly Erin, acknowledging that it had been a real team effort. They were just in time for the Christmas rush!

Turangi residents were proud to show their friends the new shop and it was a welcome addition to their community. Donations were being received on a daily basis. The burgeoning Turangi Shop now employed Aroha French as Assistant Manager for three days a week, which gave Wayne more time to spend in Taupo. Sadly, that appointment did not last as Aroha found full time employment. Sarah Morgan was then appointed. Sales of goods were going well, and volunteers were plentiful. Their skills improved weekly, while good donations continued to be received on a regular basis. The first birthday of the shop was celebrated with cake and phone calls from Trust Board members. The shop had a visitors' book with some lovely comments in it and Wayne was keen that the Taupo shop should have one too.



The Vines Fashion Parade was held on the 22<sup>nd</sup> August 2013 at the Vines Café in Taupo. Both Lianne Fraser and Wayne were "models" for the evening, and it was a lot of fun. A good turnout on the night and a lot of laughs.

The Hospice Shop's second birthday was held in the week 26<sup>th</sup> through to 31<sup>st</sup> August. Extra special sales were changed daily. Birthday cake, balloons, birthday signs and lots of energy from the team added to the overall success of the week. On the final day, the Saturday, a sausage sizzle, face painting and a musician was organised.

By November 2013, the Trade Me site was up and running and a dedicated volunteer appointed to co-ordinate it. Wayne had put a huge amount of time and effort into both shops and this was acknowledged with grateful thanks from everyone concerned when he resigned. Mark Wisniewski took over the job of Manager of both shops. Both shops continued to grow and flourish and are now the biggest source of regular income for Lake Taupo Hospice.

### **Creative Catwalk**

Hospice Shop Manager, Donna Ferrall, had always been keen to get more people, particularly younger ones, involved with the Hospice, and in 2013 she came up with the idea of a Creative Catwalk. Based on the WOW (World of Wearable Arts) shows in Nelson and then Wellington, and organised by herself, Lyn Young, Elaine Chapman and Shul Gordon, the first Creative Catwalk was held at the Taupo Golf Club later that year. It proved to be an instant success, not only raising \$5,200, but also involving schools in the area. "These big events started to get Hospice on the map and we understood that it was very important for Hospice to have that public face." Suzie Kuper

A lot of work had gone on beforehand though, with Donna and Lyn firstly visiting the various schools to ask them if they would be prepared to incorporate it into their curriculums. They certainly would! Together with the teachers, various categories were put together, with one involving the students having to come into the Hospice Shop to buy items they would need to make their creations. A logo was designed, friends were contacted and became involved. "We were blown away." said Donna. "The schools were just so supportive." The show wasn't just for schoolchildren though, people from Rotorua and Turangi entered too. It was such a success that it was agreed that a similar event would be run in 2014, only this time the aim would be to raise \$10,000.

The following year's event was far more ambitious affair with a wide range of categories on offer from pre-schoolers *Hats Off for Hospice* (creating a fun and funky hat), through to environmental and couture garments and the *People's Choice*. This time it was held in Taupo Nui a Tia College's hall, with their hospitality students doing the catering. Tauhara College was involved with the photography and students from Taupo Nui a Tia were responsible for the sound. The dream of "bringing the hospice to the kids" had been realised. The hardworking team of workers involved in the affair were rewarded with an amazing evening which exceeded their hopes by raising \$20,000.



By now Harcourt's was involved, sponsors were on board and it was time for Donna to step down and leave things to her excellent team of volunteers. Planning for the 2015 Creative Catwalk began early. Much had been learned from previous events and some changes were made to improve the way it was run. In addition to the support from local sponsors, a variety of excellent auction items were donated by local businesses, tickets sold well and with the meticulous planning of the committee, everything went magnificently. Winning the Supreme Award for the year at the local Trustpower Community Awards later that year was the icing on the cake!

In 2016, designers from Tauranga to Turangi had entered for what was by now Hospice's biggest annual fundraiser. Entries were received from professional designers, college students and primary school children, with four categories being showcased: Junkyard Invention, My Big Fat Gypsy Wedding, Pak 'n Style, and Hospice Couture. The youngest designer was five and the oldest about 65. Thanks once again went to the organisers, tireless committee, and volunteers of this popular event.

Creative Catwalk continues to be a huge success story, and at the time of writing (2019), it is still going strong, with the Great Lake Centre being its new home.



Creative Catwalk 2015





# **Changes for the Future**

The year 2012 began with a number of meetings, including a special meeting attended by Alison Bowman, Suzie Kuper and Trustees David Maling and Bret Butler, at which Suzie explained how the increase in patient numbers from 40 to 60 was impacting on their already committed work force. The ability to provide the level of massage service and the vital delivery of equipment was also under great pressure. It was resolved that an immediate approach be made to the Lion Foundation for funding of \$28,800 to support therapeutic massage. An application was also made to the Transpower Community Care Fund for a grant towards the purchase of an equipment delivery van, complete with hoist - this would be invaluable, particularly in poor weather.

It was necessary to identify the requirements of Lake Taupo Hospice in terms of goods and services, so that timely applications could be made to suitable Trusts for assistance throughout the year. Bret had already drawn up lists of possible Trusts and had set out the progress of applications made to date. Discussions were held about how best to identify projects which would require funding, as well as future funding demands.

LTH now had a database which identified people receiving its newsletters and who might be willing to make Hospice their preferred charity. It was important to keep them fully informed of everything that was going on and make it easy for them to donate.

A second-hand Toyota Rav had been bought for \$16,250, with donations of \$10,000 being received towards its purchase from Stretton and Co and The Trusts Community Foundation.

2012 saw the Ministry of Health producing new work processes which District Nurses would have to adhere to. Palliative nursing could no longer be given priority under the terms of the new contracts which meant that District Nurses would be unable to provide a service that would meet the standards of Hospice palliative care. This was happening across New Zealand and Julie Eilers reported that all hospitals were faced with the same dilemma and were relinquishing their nursing contracts for palliative care. Taupo Hospice staff already felt that they were picking up the extra work that the District Nurses were unable to handle and were keen to provide a seamless on-time service which would mean less stress for patients and their families. Lake Taupo Hospice contracted for the palliative care services and was successful. As patient numbers had trebled over the years more staff were needed to ensure that the service could be delivered to the highest standard and be able to move forward in the longer term.

Suzie did a study to find out the best way to go about providing a new model of care for Taupo Hospice and how to set up that model. Her own role was already changing to include more patient care and less administrative work. Alison and Terri would now help to take some of the load which she had previously handled.

Bronwyn Harmon, who had been employed on a short-term contract to set up a fundraising system, was working to identify areas which needed improvement, as well as sourcing new avenues for raising funds. In April she presented a review of options for a Hospice Fundraiser Database and recommended the Fundraiser Anywhere system, which was used by many hospices around New Zealand. This system would allow the capture of usable and vital information from donors and supporters which would be invaluable for fundraising.

By May, plans were in place for the transition phase of community nursing which would begin on the 1<sup>st</sup> of July. Bronwyn emphasised that the changeover to the provision of palliative care for the Taupo district community needed to be communicated to the public and Multi Media services agreed to put together a media plan which they would implement as Pro Bono work for the hospice. Costs for the changeover were estimated at approximately \$40,000 and the new fundraising strategy would be used to ensure that this amount was available.

Suzie and the staff had been discussing how best to roster the 24/7 care required under the new contract. Suzie had put in a tremendous amount of work into this transition and had no doubt that the community would benefit from the proposed new model. David Maling had written to the District Nursing service and the hospital, thanking them for the support and care they had delivered on the Hospice's behalf and had reiterated that everyone needed to continue to work together for the benefit of the community. David met with Mary Smith and Vanessa Russell to see if some of the upfront costs created by the change of direction could be met.

He warned that Hospice would have to streamline its approach to finances as costs associated with employment, such as vehicles and some medical supplies, would leave no margins for additional spending. At the April Trustees' meeting David warned that the budget for the year would be tight and that they would need to progress with a careful balancing act to ensure that they were not seen to be too parsimonious, thereby killing the enthusiasm of supporters. Delivering vital services was paramount and he was confident that, with their record of imaginative thinking and securing funding for changing requirements, the committee would manage the changes in the new delivery services.

A meeting of the Taupo Moana Rotary Club was held at Hospice, with Alison giving a presentation. The club gave a very generous donation in memory of three of their members and there were further offers of help with architectural drawings as well as donations of wood for the 'woodshed' and a printer/photocopier. It was becoming increasingly difficult for everyone to work in the current premises, with people doubling up in offices, more nurses joining the teams and people sharing the "garage" office because of the lack of space. It was challenging to find a quiet place to talk to patients, family members and new staff as well as staff meetings. The bathroom had to be used on several occasions!

The Friends had managed a stall at the Home and Garden show in April which resulted in a couple of donations and a few new volunteers. It had been a good PR exercise and a cheque for \$1,500 was received from the Antiques show and \$500 from Jolly Good Fellows. Graeme Pringle had been the chief organiser for the Golf Tournament held on the Centennial Course in May. Fifteen teams entered and \$3,360 was raised, with almost everyone receiving a prize of some sort. Sadly, the car provided by the Cooper Family for a hole-in-one, was not won! The Night to Remember had also gone well with a profitable result being recorded and Pauline de Lira's Tea Dance was once again well supported.

After years of unstinting hard work, Hugh Treadwell stepped down as Chairman of the Friends at their AGM. David Maling thanked him for his contribution to Hospice where he and his wife Sue, had been such strong supporters for many years. That September, Hugh was honoured to receive an award from the Governor General for his many services to the community.

A report of the 13<sup>th</sup> of June noted that the Fundraiser Database was growing. Current donations were inputted, and three volunteers were working on recording donor details. This was meaningful data for future funding. Out of a group of 356, only 49 Friends of Hospice had paid their annual subscriptions and as a result, the subscription fee of \$5 was removed and members moved to a direct mail programme to be targeted for regular giving.

An extensive Fundraising Plan for Lake Taupo Hospice 2012 – 2013 was ready. This covered communications, bequests, community fundraising, Friends of Hospice, general donations, donors, Hospice Shop, the Hospice Beef Scheme, and Trusts and Foundations. With the changeover to 24/7 palliative care service starting, there was a short-term plan to meet the cost of implementing this as well as a long-term Hospice fundraising plan.

In May Suzie nominated Janine Colpman-King for the Nursing Leadership Award, citing the important part she played in educating support workers about the skills required to deliver Palliative Care. Her intelligence and creativity were noted as well as her ability to communicate clearly. Judy Tunnicliffe was welcomed to the role of Community Nurse, joining the nursing team as a very respected District Nurse who was well-known in the medical profession and the community. Sheila Roberts, Patient and Family Support Co-ordinator, was grateful to the team of counsellors for their support, as that emotional and physical support needed by both families and patients using Hospice made such a difference to their lives.

Alison Bowman, the Volunteer Manager, had had the largest number ever of 'hits' on the website, due in part to Hospice Awareness Week in May and the shop window competition held by the Friends. A volunteer meeting about the future of Hospice had been held and the turnout had been wonderful, with enormous support and goodwill from all volunteers. A Volunteer Appreciation party had been held at Suncourt Hotel, the venue donated by Suncourt, with the BNI group once again helping with afternoon tea.

During 2012 the BNZ donated \$1,100 to what was initially called the Hospice Cattle Scheme. An account was set up and it was agreed to add a further \$5,000 to initiate an innovative new partnership between Hospice and the BNZ. The idea was that farmers in the region could donate, sell or graze cattle purchased by Hospice, and the profits would go to Lake Taupo Hospice. To distinguish the Hospice cattle in their herds, they were identified with bright orange ear tags. A timely donation from the Collin Craig Estate of \$3,008, which assisted with this scheme, was warmly received.

After discussions with Leanne Vlaanderen, the Fundraising Manager, Paul O'Hagan, the Farm Manager at Tauhara, agreed to come on board the Farming for Hospice journey and took some ear tags for cattle. Meanwhile an adjoining farm manager was also looking at joining the scheme. Hospice now needed a volunteer with farming knowledge who would be able to liaise between the farmers and themselves. The search was on. In 2015 Leanne was put in touch with David Wilkie who agreed to become involved, bringing with him a wide range of expertise, assistance, and knowledge. As a stockman working at the sale yards for Central Livestock, he had many valuable contacts and great ideas.

At the AGM of the Lake Taupo Hospice Trust held on the 20<sup>th</sup> of November 2012, resignations were received from David Maling, Jacky Gartner, Ailsa Gathergood and Bret Butler. Erin Jones was re-appointed as a Trustee to represent the Community. No decision was taken as to who would be the volunteer representative to replace David Maling and a Trustee to represent the Lakes District Health Board would also be advised in due course.

With the passing of Tana Wall, it was agreed that the Trust would encourage Te Nohanga Kotahitanga o Tūwharetoa Iwi Health Governance Group to appoint Peehi Wall with Fenella Hodgkinson continuing as representative.

There were no nominations for the position of Chairman, and the Trustees agreed to a proposal to work through various options over the following three months, after which the Deputy Chairman's position would also be addressed. Gill Jones was elected as Secretary, Denise McKay as Treasurer and the auditors would be Dickson and Co, subject to their approval.

Maurice Gianotti thanked the Trustees for their support and also expressed the thanks of the Trust to David for his excellent leadership during what had been a very challenging and successful eight years, while Peehi thanked the Hospice as a whole for the care given to Tana and the past happy association.

# **Day Stay and Bucket Lists**

"Some of the patients had specific bucket list wishes which they wanted to carry out before they died and wherever possible Lake Taupo Hospice tried to fulfil those wishes. Racing round the car track, taking a kayak out on the lake, and having a flight in a glider were only some of the requests that dying patients have enjoyed.

Tom Anderson, co-ordinator for gliding club, has always been happy to take a patient up for a flight, even with the risk of the patient blacking out while up there. Most patients would rather die doing something they loved than sitting around waiting for it to happen.

One young patient wanted to experience the speed of the racing car track. "I remember her climbing out of the car, shaking, and me thinking, "What have we done!" We asked her how the experience was, and she replied, "That was the best thrill of my life - 230 kms down that track." She taught us all what it meant to be young and dying. She needed to go into residential care because both of her parents were frail and elderly and couldn't look after her. Residential care looked after her so beautifully.





Some wishes do come true..

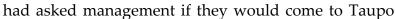
One young woman wanted to die with bright glittery fingernails – the glitter to remind her of the stars and the deep purple to be the inky black night. She wanted to travel into the night at the end of her life. Marie Beadle, a beauty therapist, donated a lot of her time. We rang her to let her know that the patient was semi-conscious, and we didn't know if she was going to be conscious enough to have her nails painted. We knew that this was the patient's dying wish and the beauty therapist didn't blink an eye, off she went and did her nails. When the patient's nails were done, she squeezed the therapist's hand and waved her fingers so, although semi-conscious, she did know that she had had them done. Little special moments like these really made the difference.

There was a young guy who had a rare life-threatening condition. All his family members had died through heart, liver or kidney failure. His wife was working fulltime to keep the home fires burning and he was sitting at home, wondering what he was going to do with his life. One thing he did well was build possum traps, so when Hospice moved to Huka Falls Road and they needed possum traps, he built those for us.

Wha McLean initially came on board as a volunteer to help families get their finances in order and understand what needed to be done. There was a chap who had been a reporter for the NZ Herald, and he lived in a double-storey house. His office and all his financial records were downstairs, and he could no longer get up and down the stairs. There were unpaid bills in amongst the piles of paperwork and he was stressed because he couldn't get down to his office or see well enough to go through all the paperwork. He asked if Hospice could get someone to help him sort it out.

Wha arrived and the patient was so relieved. He said, "When my daughter arrives, she is going to be so mad at me!" Another thing that worried him was that he hadn't pruned his wife's roses. His wife had died, and the roses were looking bedraggled. Wha helped him to sort his paperwork into piles of 'need to keep', 'didn't matter' and 'urgent action' for when this daughter arrived. It was all done, and the roses were pruned. Wha went anywhere, anytime, anyplace and to any family, and Taupo Hospice sent him to some tricky families to help get things sorted out. There are so many good people."

Hospice House at Sunset Street needed to be extended. John Wallace had organised for the Bay of Plenty Community Trust to come on board and have a fundraiser with the Topp Twins to assist with the extension to Sunset Street. There were a few Hospice patients who were absolute Topp Twin addicts but were too unwell to go to the concert. Hugh Treadwell





Hospice, but was told they were far too busy. The next minute, the Topp Twins turned up at Sunset House! They were delightful. They wanted to know all about Lake Taupo Hospice and said they would come back after the concert if we could get some Hospice patients together. One of the patients was Josie Wall and all her life she had wanted to learn to yodel. The Topp Twins came with us down to Waitahanui and we gathered as

many patients as we could into her house. They put on a concert in Josie's bedroom, in bed with Josie, singing along and having a wonderful time. The private concert went on longer than expected and the Topp Twins missed their flights out of Taupo, so one had to be driven to where she was meant to be and the other had to book a later flight.

#### **Hospice Moments**

"Giving a voucher and information for entry into V8 car racing at the Taupo race track was a privilege. This patient's husband describes his wife as "a V8 maniac" and even their door bell is the sound of a V8 engine. The lady struggled to find words to thank us, but the smiles and tears said it all. It was also nice that she was able to enjoy the day with her husband and friend."

"The journey with massage is so important for those of us that have the privilege of being able to receive this service. It helps us to feel our physical body and experience where are pains are, and the soothing and healing effects of that touch that comes with this work. Many of us who are on our own have no-one to touch us in a safe way and this is vital on the journey of recovery. Ongoing treatments are very important as there is a flow-on healing that continues over a period of time and one just doesn't do it." (Written by a patient)

"A young woman struggled with the long course of chemotherapy in the hope that it would prevent further spread of her cancer. The day I visited she looked frail, unkempt and bedraggled and I was aware that this is not usual for her. After discussion around symptoms etc, I offered her some personal care in the form of manicure, facial, haircut and massage.

I did not expect her to respond that she would absolutely love to have this attention, but not until just prior to Christmas. She explained to me that this was when her chemotherapy was due to be completed and the it felt like the light at the end of the tunnel. There was absolute delight on her face as I could see her travel in her mind to that time, and she expressed the feeling of being really spoiled. As I departed, she expressed anticipation of that time and that she would come and spend the day with us at Hospice in Taupo."

"This month has been extremely busy, and the freezers have been replenished often as the demand for meals has risen. An example of the appreciation is: Mrs N is very frail and struggling to eat at all. Her daughter is very concerned and has served her a range of meals intended to tempt her. I had delivered several meals on my first visit. I will never forget Mrs N as she told her story. "I said to my daughter, bring me some of that mush Janet brought me, I'll try some." She then explained of her daughter "she knows how to heat my food just perfectly, warmed right through, but not hot, and only a small amount on a plate. I loved the lasagne so much so much they could not believe their ears when I asked for more and yet again for another helping — absolutely delicious." The beautiful warm and cheeky smile said it all. She was very pleased when I asked if I could pass on her thanks to the other Hospice staff and especially to all the volunteers that provide the means and baking. Such a small gift is very much appreciated." (Hospice nurse)

"A patient I'd like to tell you about is a chap who was in Monte Vista Rest Home. He was only 51 years old. He'd had a stroke which left him unable to speak and with a dense hemiplegia on his right-hand side. He'd been in the rest home for four years when he developed cancer of the kidney which started to bleed and despite palliative radiotherapy and some other measures to stop the bleeding, it was unable to be done. He had to make the choice whether to continue to have blood transfusions or to have them stopped, and he chose to have them stopped. He was quite a young Maori gentleman. He lived on a very remote marae and his biggest wish was to go home to die in his own bed at home which he hadn't seen for several years. Because of the need for transport and a bed, we rang the ambulance service only to find that it was going to cost the family \$350 for transport home to the marae. This was going to cause considerable financial strain on the whole family, so we had to look at what our other options were. While I was busy organising for one of our Hospice beds and a Hospice lazyboy, a horse float arrived. It was the polo club from Turangi who had come to collect the equipment. As we were pushing the bed into the back of the horse float, we looked at each other and said, "Why isn't the patient in this bed?" The horse float had electricity and it was extremely flash! It had beds for the family in there; we had room for the lazyboy, so we all looked at each other and laughed and thought well this is absolutely perfect. This is something that the patient would really appreciate, being a horse man from way back. So, we took the horse float up to the rest home and put it to the staff and his family who all thought it was absolutely hilarious. A great idea, so the patient was transferred into the horse float in his Hospice bed and he travelled very comfortably home in that.

He was taken out to the bush which he loved so he got to sit out amongst the trees and have his pig dogs in the back of the horse float with him and then he was able to see his horses again and he died two days later at home surrounded by his animals, his friends and family. He was transported to the undertaker back here in Taupo in the horse float! Judy, some of the volunteers and his family had a little bit of a celebration of his life here in the Hospice grounds which was quite special."

"One of our patients is a young girl, 34 years old and she has sons of 18, 6 and 4 years. She relocated here to start a new life for herself some 5 years ago and presented at the doctor with pain in her hip, only to discover that she was riddled with secondaries from a primary cancer of the breast. Her secondaries are in her brain, liver, hips, ribs and her spine so her prognosis is not good; in fact, the time she'll have left looking after her children is extremely short. So we recognized the need to do something special, very quickly for this family and Judy and I spent some time planning a special weekend for them and, courtesy of House of Travel, our sponsors, we sent this family to Auckland. The family spent a special weekend in Auckland with the help of St Joseph's Hospice."

Fiona MacDougal runs the day stay programme on a Friday and makes sure it has a good mix of everything. Arts, crafts, poetry, music, storytelling, and singing. Whatever the particular group at the time needs or wants, Fiona makes sure it happens. It is aimed at the patient, without the carer being there, what that person needs and how they can be occupied when they are at home. Day stay has more of an occupational therapy bent to it, learning what the patient is good at and how they can be helped to be good at that for longer. Tuesday Club is more of a social day which the carers can attend too.

Friday is the creative day. Arts have always been a big part of Hospice. One of the patients was a local artist and said that he had so many unfinished paintings but just didn't have the energy to set up his easel or brushes. At the same time, we had a patient who had moved from Tauranga. She had been told she had only weeks to live, but the doctors managed to put a stent in to keep her airway open and all of a sudden, she went from having weeks to live, to months or maybe years. She had sold her house and come to live with her daughter in Taupo. She had to be careful as she could aspirate during meals, so she had to have someone with her whenever she was eating or drinking. We did the tour of the residential facilities and she chose the one with the best arts programme. She used to paint enormous canvases and they made one of their storage facilities available for her. She asked if we would mind if she came along and painted at Hospice House.

So other artists, like Jennifer Cook-Battersby came along and helped set up. There were three Taupo artists who assisted, and they would paint and discuss art with the patients. Barry was another chap who had been a scientist and he had never wanted to be a scientist, but his mother wanted him to. All he ever wanted to be was an artist. They helped him complete four canvases, one for each of his children, before he died. Pat Vesey used to run that group for a long time. Wonderful stuff like that happened.



There is a big need out there for more day care centres. Not everyone wants their loved one to go into residential care, but the carers do need a break. There is an ongoing need for community drop-in centres where people can be cared for whilst their carers are at work.

Years ago, it was difficult accessing occupational and physiotherapy through Taupo hospital, and it was important in keeping the patient functional. Katie Noble, an occupational therapist, had left Taupo Hospital as she had recognised the need for community rehabilitative services and started her own business. She got the ACC contract for "falls and prevention" across the whole district. Palliative patients are high falls risk. Katie had her own equipment and access to specialist services when help was needed. She would sit alongside Fiona, who has an occupational therapist background, and taught her what she could teach patients on a Friday. Katie helped Fiona set up that programme and made sure we could access her team's expertise.

# Lake Taupo Hospice Development Trust Formalised

By the February 2013 meeting there were still no candidates for the position of Chairman, and Maurice Gianotti asked the Trustees to come up with suggestions for possible nominees prior to their next meeting. With the passing of Ratana Wall the previous year, the Te Nohanga Kotahitangi O Tūwharetoa Iwi Maori Health Governance Board had appointed a new representative to the Trust. Ned Wikaira was the new Kaumatua and Peehi Wall remained associated with Hospice as Kuia.

At the start of the year Suzie had emphasised the need for the next trustee appointment to be someone with experience in healthcare, and the March meeting saw her stressing the need for a .6 nurse to assist her with her workload so that she could manage the accumulated amount of administration work. As a result of this, it was decided that a sub-committee should meet to research how best to alleviate Hospice staff shortages. After consultations and interviews, Maggie Pleydell was appointed later in the year as a .6FTE Community Nurse on a fixed hour contract.

In April, acting Chairman Maurice Gianotti thanked Britten Draper for their most generous free accounting services for the past seven years. The new accountants would be DPA Chartered Accountants and the transference of records from Britten Draper was then organised. Maurice also congratulated the staff on the excellent findings of a recent Patient Survey, saying that the Trustees were thrilled with the result.

With the resignation of Fiona Smith Cutting, the Trustees confirmed the appointment of Lianne Fraser as the new Fundraising and Promotions Manager. A paper covering the findings and recommendations of the review group on Fundraising Structure had been drawn up and if the Friends were willing, the Friends Trust would be wound up and a new title decided on. Alison reported that the Friends committee had approved of a new name – the Hospice Friends Events Committee - and agreed to wind up their Trust once all members had been notified prior to their meeting in June.

Several funding applications were approved, including a further \$10,000 received from the John and Wendy Norwood Trust for continuing Pal Care software, the NZ Lotteries Commission for the Volunteer Manager, Southern Trust towards wages for the patient and family support worker and the Lion Foundation for funding towards the wages of the massage therapist. Further applications had been made for advertising by Timeless Taupo and to the Craters of the Moon for a syringe driver with an approximate value of \$2,600. The Creative Community Scheme were also approached for funding for art supplies. The Hospice Street Appeal had brought in \$1,000.

Lianne Vlaanderen proposed that an experienced fundraising consultant be engaged when the time came for fundraising for capital projects. She offered to research prospective consultants and to develop a fundraising proposal. While the Trustees were reluctant to incur further expenses at this stage, it was agreed that to maximise the value of the programme in place, more hours should be spent receiving training with Bronwyn Harmon. A further five hours at \$42 per hour was agreed to.

Jeremy Irwin had drawn up a report on future development which included plans for the possible expansion of Sunset Street/Puriri Street. There had been numerous complaints to the TDC from residents re the growing number of cars in Sunset Street and due to increasing pressure, the TDC queried what the future plans were for relocation.

With the formation of the Lake Taupo Hospice Development Trust, the LTH Trust resolved "That the Lake Taupo Trust Inc. confirms the previous resolution to transfer the sum of \$400,000 during the financial year ended 20<sup>th</sup> June 2013 to the Lake Taupo Development Trust Inc. and such transfer to be a distribution from the Trust in terms of the Trust Deed."

At this stage, the Development Trust committee had already investigated various potential properties for proposed future development, but none of these had come to fruition. However, the option of the Taupo District Council's site at County Road was now re-opened with TDC support, and a Geotech investigation of the site by Mark T Mitchell Ltd was implemented in April. This enabled an assessment of the viability of the land for building a proposed hospice. A conditional lease with the TDC met with the Trust's approval and it was decided that Jeremy Irwin, Committee Chair for Lake Taupo Hospice subcommittee, would handle communications and advise on all matters regarding the sensitive issues surrounding this possible expansion. In a wonderful gesture, businessman and philanthropist Richard Izard made known his intention to gift \$1.8 million to help with the project.

In May, the Trust and staff hosted the Lake Taupo Hospice major supporters at Izard Air. It was a great event and fitting recognition for the contributions made by those generous supporters.

As the year moved on, John Picot, acting as Chairman in Maurice's absence, advised that Terri Foley was proceeding well with the Strategic Plan and that the draft Plan would be available for the Trustees' perusal and amendments by mid-September. The final Plan was presented on the 7th of October and it was moved and seconded "That the Strategic Plan be adopted in principle and a sub-committee of Brian Bockett, John Picot and Maurice Gianotti be set up to work through the details with the heads of each section."

Alison Bowman suggested running biography courses to raise some additional money. For financial clarity, the extra hours she worked for these would be treated differently from her wages. Good feedback was received from other hospices on the "Fundraiser" database programme, although more time operating it was necessary to learn it properly.

During the year Alison had nominated the former Lake Taupo Hospice Chairman, David Maling, as a recipient of the Local Hero regional medal for his volunteer work with the Hospice for over 11 years, including his eight years as chairman. A reluctant Hero, David said "I don't really feel the award is for me alone - it's for the Hospice and all the staff and volunteers who help out generally."

The Trustees' meeting in November saw a sub-committee present a list of possible candidates for the positions of Chairman and Trustees. After much discussion it was agreed that Maurice would approach acceptable personnel and report further.

At the AGM on 17th December 2013, Maurice Gianotti agreed to act as Chairman until March when Alan Vane would join the Trust, having accepted nomination as Chairman. Nominations for Deputy Chairman would be deferred until that happened. John Picot, who had been co-opted during the year and had stood in as Chairman during Maurice Gianotti's absence overseas, had given notice that he would be standing down due to ill health and Phil Clarke who had been also co-opted during the year, resigned from the Trust, while Anna Dawson agreed to come on board. Fenella Hodgkinson would continue as the Te Nohanga Kotahitanga o Tūwharetoa Iwi Health Governance Group representative and Ned Wikaira as Kaumatua, with Peehi Wall as Kuia.

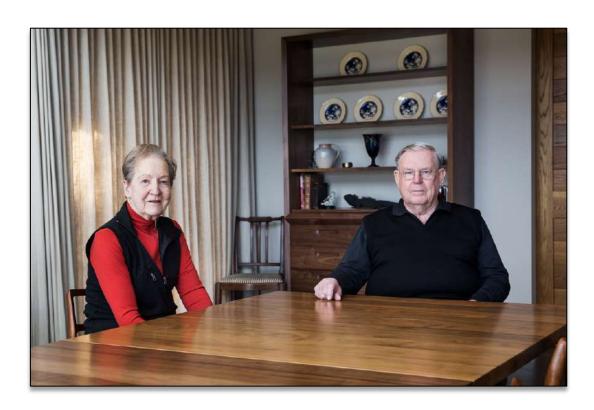
No Trustee had been found to represent the Lakes District Health Board, despite several requests during the year. From the group of four Trustees, Maurice, Jeremy, Brian and Erin, one would represent the Volunteers of Lake Taupo Hospice, leaving three to represent the community. Maurice was commended for accepting the Chairman's role for the whole year and sourcing new Trustees to join the Trust.

Suzie reported that the addition of Maggie Pleydell had made a great difference to alleviating the heavy workload and recommended that her nursing position be made a permanent one. This was duly agreed to by the Trustees. Suzie also voiced concern that there was no Maori representation on the Lake Taupo Hospice Development Trust.

The December 2013 Volunteers' newsletter laid out the following statistics which reflected just how much the volunteer services had expanded over the past five years:

2008	2013
Approx 28 patients at one time	Approx 70 patients at one time
43 volunteers	217 volunteers
A garage sale operating one day/week	Two shops operating total of 9 days/week
No administration volunteers	Six administration volunteers
No handyman volunteers for patients	Three handyman volunteers for patients
Lions team delivering equipment	Lion's team + 5 volunteers delivering equipment

A breath-taking donation of \$1.8 million from Richard and Patience Izard was received in December 2013. This meant that a fantastic new hospice would now be able to be built!



Patience and Richard Izard in their Taupo home

# The Expansion

February 2014 saw acting Chairman Maurice Gianotti welcome new Trustees Alan Vane and Alan Payne, as well as new Fundraising and Promotions Manager, Leanne Vlaanderen, to the first Taupo Hospice Trust meeting of the year. There was much to report on.

Brian Bockett (Chairman), Gary Chapman, David Maling and Erin Jones had been joined on the Lake Taupo Hospice Development Trust by co-opted Trustees Maurice Gianotti and Jeremy Irwin and it was agreed that Delani Brown should also be invited to sit on the Trust in order to ensure that Maori cultural involvement was part of any major decision making.

After a great deal of work, planning, discussion and consultation, it had been finally decided that the County Avenue land was not a viable proposition for a new hospice building, as there was a caveat on it with the Maori Corporation. This meant that they would never be able to totally freehold it, nor would they be able to raise money on it at a future date if necessary. There was unanimous agreement that there was strong preference for building on freehold, rather than leasehold land.

David and Jeremy met with the Mayor, councillors, and consultants to discuss the purchase, proposed development and funding of up to 1.8 ha of TDC land adjacent to Marshall Avenue and the Waipahihi sports complex. The land adjacent to Marshall Avenue was exciting as the area was central for the community and offered a clean field with good views.

At this stage, it had been estimated that the design concept, documentation and tender would take approximately 25 weeks to complete and the building, eight to nine months. The position of Project Manager would be advertised in the Dominion, the New Zealand Herald, the Christchurch Press, the Taupo Times and Rotorua Mail to ensure absolute transparency in the selection.

The TDC approved the Trust's proposal in principle, but there were more formalities to be gone through before building could be progressed. By May, after a complete assessment of proposals from three companies, Gavin Robins' Reckoninc was appointed as Architect/Project Manager to work with Cheal Consultants, who were commissioned to prepare a costed site plan for the building. This went ahead while various approvals were sought. Sadly, this proposal did not proceed either as the TDC's long-term plan precluded the development of this area until the land nearer the airport had been developed. Should Hospice have wished to proceed, then they would have had to pay and install all the underground development, water, sewerage and power and also build a link road from the site to Marshall Avenue, to a standard suitable to TDC. The two trusts in conjunction with benefactors Richard and Patience Izard, agreed that this was a detrimental cost.

On the nursing side of things, Suzie's first report of the year outlined staffing proposals and changes to working hours which were duly agreed to. She also suggested that a concept to embrace the spirit of hospice being for all people, which would tie the history of the Sunset Street property to the new land and buildings, could be appropriately celebrated with a sculpture by Delani Brown. It was agreed that 'An application be made for funding to the Taupo District Creative Communities Scheme for a sculpture to suit this concept.'

Tributes were paid to Janet Gainsford, who had died unexpectedly. She had been a wonderful asset to Hospice and was loved by everyone there. As Suzie said "Janet, our most senior palliative care nurse, was my right hand and a champion/fighter dog with a bone for the wellbeing of the whole family/whānau in hospice and palliative care. We won't try to replace Janet – the boots are simply too big to fill."

Alison Bowman noted that now that the Friends' group was officially dissolved, Lake Taupo Hospice no longer invited the public to attend meetings to meet the Trustees and ask questions. She suggested that this should be a regular event, especially with the development progressing.

At the start of 2014 Alison had once again organised educational sessions for all volunteers, and those who were working with patients were expected to attend at least five per year. Among the excellent new volunteers who had joined Hospice were two administrative assistants and three equipment delivery men. With the five new biographers going through their training, some new digital recorders were needed, and it was hoped that these could be sourced through a grant application. The purchase of a binding machine also meant that complete biographies could be processed 'in house.'

The recently established role of Volunteer Manager for the Trade Me site was working well and achieved higher prices for many items than would have been gained through the shop. By the middle of the year Alison reported that a stream of new volunteers needed to be orientated and said that she would run an additional orientation session to get as many people as possible on board. Total volunteer numbers were now 241 and total volunteer hours per month were regularly exceeding 1,700 hours.

The first meeting chaired by new Chairman Alan Vane was held in April. He acknowledged the wonderful service that Maurice Gianotti had given to Hospice over many years. Erin Jones' retirement from the two Trusts was greeted with sadness. Her contribution to them had been enormous and her support for both Donna and Wayne at the Hospice Shop had been invaluable.

Suzie gave a short presentation on one aspect of the recent Hospice NZ CEO and Trustee forum. This covered how palliative care was perceived in the community, what community engagement meant for the hospice and how best to model services in the future. She said that the focus should be on moving forward rather than on problems, and that assets, namely staff, volunteers and Trustees, should be the primary focus. Quality action came from collective thinking and building on the strengths of the people in the organisation. She later reported on the positive Peer Review by Hospice NZ. Jenny Matthews from Hospice NZ recounted that none of the bigger hospices were close to providing the services given by Lake Taupo Hospice. Suzie said that she was proud of what had been achieved.

Alan Vane stressed that it was important that the community wasn't being left behind as the organisation moved forward to the next "corporate" phase. He strongly supported the re-establishment of a Friends' Group and it was agreed that the AGM would be open to the public.

Leanne reported that a fundraiser database had been established and that fundraising goals were being set. The focus was to target existing corporate sponsors whilst pursuing new opportunities with other corporations. A function was held at Parawera to thank and acknowledge Hospice's top 30 supporters for the year May 2013 to May 2014.

St Patrick's Day was celebrated at Jolly Good Fellows with the proceeds from all Beef and Guinness pies sold, going to LTH. This venture proved to be an outstanding success. In another fundraising venture, Dilmah Tea Hospice Cuppa packs with invitations were available, with recipes and tea bags supplied by Dilmah and coffee donated by Caffe l'affare. Farmlands had also held a successful fundraiser with a 'Hole in One' competition and concert.

Public meetings for Hospice Awareness Week were held in Taupo and Turangi in May and both attendances and media coverage were good, with the Taupo Times, The Weekender and More FM coming to the party and Leanne being interviewed live by Andrew Leiataua on More FM.

Lake Taupo Hospice Trust was looking to establish an Endowment Fund with the Geyser Community Foundation. A working group consisting of Leanne Vlaanderen, Alan Vane and Denise McKay had been established to this end and there had already been some preliminary talks. It was resolved that the Trust would submit a grant application to the Waiora Community Trust for assistance with expenses associated with Lake Taupo Hospice Clinical Education Programme.

The carving of Tane by Delani Brown was completed and was unveiled at a beautiful ceremony on the 14<sup>th</sup> August. The carving was created from 1,800-year-old Totara that once stood at the base of Mount Titiraupenga. The rakau (wood) for this project was donated by Helen Gray in memory of the care and love that Hospice shared with her.



"Tane is presented here in abstract form which acknowledges Tane as the first human created, making him the original seed of mankind. In other beliefs systems Tane could be looked upon as Adam. When we understand Tane, we begin to travel inwards to understand the genealogy of man, the potential of man and the tree of life that links all people together."

Delani Brown

August also saw Kim Gosman of Tūwharetoa Health Services being welcomed onto the Trust to represent the health and welfare area. All the Trustees were very much in favour of her appointment.

As August was a particularly busy month for compiling charitable trust applications, Luisa Mikkelson was employed for an additional two days per week for four weeks to assist with these. She had already compiled a new charitable funding database, updated with valuable information from Bret Butler, and applications to various Trusts for funding had been prepared.

In his Chairman's Report in September, Alan Vane noted that Rule 15(x) of the Constitution of LTH Trust Inc empowered the Board of Trustees to appoint committees, but the Rules were silent as to who might be on them, and/or what powers and functions they might have. Maurice Gianotti had prepared a Discussion Document on Board of Trustees Meetings and sub-committees shortly before his retirement from the Board, but this had not been formally decided upon. In addition, Alan spoke of the need for discussion on appointment of Trustees at the AGM and asked for feedback regarding his suggestion for an expanded list of committees. He was keen to re-launch the Hospice Friends and there was debate about how this would be done.

Alan met with Leanne and Terri Foley to discuss strategy for fundraising and the possible role of a Friends/Supporters of Hospice group. They were well positioned to assist with funding for other than operational needs and an annual donation from a Friends group would be useful, as would utilising that network to encourage bequests. A new fundraising structure would have long-term aims. The operational arm would be funded by the shop, events, grants and government funding and the long-term needs by bequests and donations.

Suzie's September report noted that it had been a very settled month for nursing and added "I have recently had feedback from Waikato Hospital staff that they have had requests from our patients for no treatments to be booked on a Tuesday, as the Tuesday Club is more important. I had first hand feedback about the importance of Tuesdays from a patient who is now tucked up in bed in the last days of life, who wanted to know what the Tuesday Clubbers had got up to in her absence, and what they had for lunch!" What a wonderful tribute to the work of the Tuesday Club team.

At the AGM held on the 18<sup>th</sup> of November 2014, Alan Vane was appointed Chairman, with Christine Knowles as Secretary and Denise McKay the Treasurer. Committees and Convenors were approved as follows:

Strategic Alan Vane

Finance Brian Brockett

HR Alan Payne

Clinical Peter Battersby and Anna Mastrovich

Fundraising/Shop Lesley McNeil

Risk Management/Health &

Safety/Quality Kim Gosman and Anna Mastrovich

Cultural/Maori Liaison Fenella Hodgkinson

Hospice Development Jeremy Irwin

The December Trustees' meeting heard Alan reporting that Hospice would receive some share of the \$20m received from Hospice NZ at the next funding round. The understanding was that \$13m would be used for historic catch-up and the remaining \$7m would go towards new services. He also commented that Hospice NZ were pro-active politically in pushing for funding for Hospice.

As the year drew to a close, the Trees of Remembrance sales in Taupo were good and with two weeks to go the campaign had already raised \$3,136. The partnership between Farmers and Hospice worked very well and the volunteers had been amazing. The Turangi Hospice Shop had an equally positive result, reinforcing the original idea that the Trees were an ongoing way of remembering lost loved ones and bringing people together.

Finally, the year ended with the annual Christmas Memorial Service and the Staff and Volunteer Christmas party.

# **Izard Hospice House**

The momentous story of 2015 was the purchase of the Huka Falls Road property in April. After a long and comprehensive search, the Lake Taupo Hospice Trust confirmed that, after ten years of operating out of Hospice House in Sunset Street, a new site had been finally been found for Lake Taupo Hospice. The search for new premises had been a long, and at times frustrating one, involving several dead ends, but it was finally over. The Huka Falls Road property purchase had been made possible thanks to Taupo residents Richard and Patience Izard and their family.

Trust Chairman, Alan Vane, said the Trust was "relieved and ecstatic" to have received funding from Izard Investments Limited to enable it to buy and remodel the well-known Stevenson family property. Although the extensive search for a new hospice site had been at times exasperating, 29 Huka Falls Road was perfect and fitted in well with the surrounding residential area.

"We would never have been able to do this without Richard and Patience Izard. The Lake Taupo Hospice Trust is forever indebted to their generosity and subsequently we will ensure the new property acknowledges them in perpetuity."

Richard Izard hadn't known very much about Hospice until his great friend Bob Burgess went into their care. It was then that he learned about all the services they offered. He said that it was an honour to witness their compassionate care of Bob and he felt that they were amazing and took great care of him. Bob and Richard had grown up together in Whanganui, so were lifelong friends. It happened that around that time Richard was looking for a philanthropic project for Taupo.

Richard's personal assistant Carol Tombleson, and her husband who was one of the local doctors, had lived in Taupo for many years. Carol knew quite a bit about Hospice and was a good friend of Alison Bowman, the previous volunteer manager there. Alison and Carol had talked a lot about Hospice, and Alison had invited Carol to the first Creative Catwalk, which was held at the golf club. Subsequently, Carol spoke to Richard about Lake Taupo Hospice as a philanthropic project. She told him how the Hospice had outgrown their premises at Sunset Street and needed to expand into a larger building.

Maurice Gianotti was the Chairman of the Trust at that stage, and he, Lianne, Richard and Carol sat in the boardroom on a few occasions discussing the requirements of Hospice and how they could fulfil those needs.

Following the decision not to go ahead with the County Avenue site, the Lake Taupo Development Trust had looked at the housing development starting on the north side of the Huka Falls Road. This included an existing restaurant, a delightful church which Richard Izard fell in love with, and several buildings. It would have been charming but was not to be. Negotiations dragged on with no definite response from the vendors, so they were suspended.

Then along came 29 Huka Falls Road. The property would provide much needed space for the various services offered by Hospice and remodelling plans would cater for the needs of the nurses, administration staff, therapists, volunteers and patients as well as providing a wonderful facility for functions such as the Tuesday Club. There was also ample space and flexibility for future expansion. The site was beautiful with stunning views and worth millions. If Hospice didn't purchase it, Richard said he would purchase it himself. His trustees were unsure about Izard Hospice House not being an in-house hospice as most people know hospice as that. Richard's trustees were insistent that they purchase the extra land which was suitable for adding a wing on at a future date.

As Richard said of his donation "I saw it as an opportunity to help. My wife's younger sister died of cancer, very unpleasantly. My brother also lost his wife at 34 from cancer. I think there was something behind that triggered something with me. I thought, "My God, can I do something?" and this Lake Taupo Hospice opportunity came up and it was just like a lightbulb."

When Richard does something, he wants to do it well and he wanted to make sure Taupo Hospice had the best of everything. The money that Richard initially offered to donate exponentially skyrocketed, probably because he wanted them to have the best facilities they could possibly have. Lake Taupo Hospice now has the land there that can be developed should Taupo reach a size as to require an in-house residence. The majority of the land and the property at the top is essential for them. Richard was looking long-term. It is one of Richard's fundamental wishes that the house and the property always be held in the name of Izard Hospice House for any future development.

Suzie mooted the idea of the house at the top of the drive being converted into a training house for home carers. It is an idea that Richard fully endorses. He formed a strong relationship with Suzie. Suzie was very aware that everyone felt comfortable when they visited Hospice House in Sunset Street and she want to create that same warmth and acceptance in their new premises.

Once again, when the building began, the need for money increased. In hindsight, it probably would have been cheaper to remove the house and build a new one, but then all the character that was there would have been lost. It would not have had the same feeling.

Patience, Richard's wife, was interested and played an active role in contributing many worthwhile ideas of how Izard House and its ground layout could be developed. Richard was so appreciative of all the bereavement care he received after Patience's death later that year.

There was much work to be done before the move to 29 Huka Falls Road, and legal possession still needed to be secured, but plans were being drawn up and remodelling would be completed as soon as possible. Architect Gavin Robins was working with a number of staff and volunteers on the plans and a set of these were on display at Sunset House.

It was agreed that a Wellbeing Centre which would include space for massage therapy, a sauna and an aqua therapy pool, be part of the concept plans and well-known gardening expert, Gordon Collier agreed to draw up the landscaping plans.

By August 2015, all the carpet had been lifted and most of it sold to assist with the cost of the rebuild. A team of volunteers were involved with selling the baths, showers and vanities and volunteer gardeners were moving some of the plants from Sunset Street to the new premises.

Plenty of daffodils and other spring flowers were blooming at Huka Falls Road and big bunches of them were picked for a couple of weeks to share with the Tuesday Club patients. Soon preparation was underway for the site to be ready for the civil works contractors who would work on projects such as widening the driveway (a legal requirement), creating the car park area and linking the two.





 $29\ Huka\ Falls\ Road\ -\ working\ outside\ and\ inside$ 

November saw the volunteer demolition team making great progress and work had begun on the grounds with the removal of the picket fence and tennis court surrounds.

By March 2016, the property had become a hive of industry and activity. Besides all the building work, volunteers began planting trees and assisting inside the house. The Development Trust reported that progress was good, with the internal partitioning, plumbing and electrical work going well. It was estimated that volunteers working on the site would have saved Hospice approximately \$40,000 by their contributions.

Then, on the 28 of August 2016 the *Farewell to Sunset Street* was held. It was well attended by past staff and volunteers, many of whom were the original "set up" volunteers. A lovely afternoon was had, with many of stories being shared. These were followed by a more formal appreciation speech from David. A new chapter in the story of Lake Taupo Hospice was now about to begin.

A Closed for Good team from the BNZ started the moving process on August the 31<sup>st</sup> as part of the nationwide Closed for Good campaign. Packing began in Sunset Street and they gave the outdoor furniture a spruce up in anticipation of the move. Of course, there were delays and hiccups, but the move finally began to take place towards the end of the year, with Taupo Furniture Removals kindly donating their vehicle and staff to move the larger items. The IT server was taken from Sunset Street to Huka Falls Road first – and then the fun began! So many people needed to be thanked when the hard work was finally over, but the hospice work continued to be central to everything despite all the distractions.

The funding for the purchase was of a capital nature and, as the Lakes DHB only funded approximately 50% of Lake Taupo Hospice's operational costs, approximately \$500,000 per annum would still need to be raised through donations, functions and grants. The Lake Taupo Hospice Trust was aware that growing numbers of people would need their services over the next decade, so fundraising remained a very important part of the work ahead.

As Josie Harris, the Family Support Team Leader, wrote in December "I would personally like to thank the team of volunteers or person/s who cut the lawns down the drive. What a huge difference it made as they looked so good for Sunday the 11<sup>th</sup> December, when Hospice was having their Remembrance Service. We had up to 60 people attending, all noticing your lovely lawns and the love that went into doing the task."

Richard Izard plants a tree in the grounds of Izard Hospice House



#### 2015 - 2016

Despite all the activities going on, nursing and support work continued apace. The Hilton Lake Taupo assisted Hospice by running a series of training sessions over the first few months of the year; based on how to make patients, customers and supporters feel important and honoured. The sessions were well attended and considered relevant to all volunteers. Some of the Hilton's team members gave the Hospice's therapy room a 'makeover' which gave both the patients and therapists a wonderfully new and refreshing environment.

After considerable planning and plenty of hard work by the committee, the Taupo Hospice Events Committee held a very successful golf tournament at Wairakei on the 24<sup>th</sup> April 2015. A very pleasing total of \$28,000 was raised, with \$9,225 coming from an auction which offered a great range of items donated by local retailers and supporters. Taupo Hospice accountant, Denise McKay, was able to report that the Events Committee had raised \$51,000 so far in the financial year. This was a wonderful result. By June, the committee was in full swing, planning the Creative Catwalk which was to be held on the 10<sup>th</sup> of September.

Hospice Awareness Week was held in May, closely followed by the Hospice Heroes function for the major corporate and community group supporters. At this function, there was a special presentation to Richard and Patience Izard from the Tuesday Club patients in acknowledgement of the very generous donation which had allowed the purchase of the new property. The patients presented the Izards with a garden mosaic featuring the Hospice Kowhai which was created by them as part of the Tuesday Club activities.

The Friends of LTH had been dissolved in 2013, but in October 2015 a restructured group was set up, with their first meeting at a Hilton Heritage High Tea. This group of financial donors each pledged an annual donation of at least \$20 per year to Hospice.

In June, the traditional Volunteer Appreciation Party held at Rotary House attracted the best attendance ever, with 90 volunteers, 12 staff members, and trustees enjoying the superb organisation. Awards were handed out, thanks given to everyone involved and, after a delicious tea served by BNI and donated by Columbus Coffee, Dixie Browns and the Hilton Hotel, Gordon Collier entertained those attending with a light-hearted speech. While thanking all volunteers, particular mention was made of the cooking and baking team who quietly give their support by making meals, delivering them for families and filling freezers.

Later in the year the Rotorua and Taupo Community Hospices were told that they were to have access to additional Ministry of Health funding (\$57,000 for Taupo) to provide some new services for people in the area and volunteers were asked to provide ideas of what they thought would improve the support and/or services that Hospice provided.

Following a nationwide recruitment search, Jeffrey Bennett was appointed General Manager of Taupo Hospice in November 2015. Welcoming him to the new position, Trust Chairman Alan Vane noted the big challenges ahead for Hospice in the highly competitive charitable sector and said that securing sustainable funding streams was critical. The board had searched for someone who was a strategic and innovative thinker for the role. As General Manager, Jeff would be overseeing Hospice's relocation to 29 Huka Falls Road.

Once again, the year ended with Trees of Remembrance being set up in Farmers in Taupo and the Hospice Shop in Turangi. As always, the response from the volunteers sitting by the trees and engaging with the public was wonderful. The many people who used this opportunity to make donations and hang their decorations on the trees showed that they felt that it was a lovely way to remember their loved ones. The final total raised for Lake Taupo Hospice was approximately \$10,000.

A slightly different Volunteer Development Programme had been set up for the year, with the focus being on specific illnesses such as dementia, respiratory disease, blood cancers and motor neurone disease, emphasis being on practical support volunteers could offer to patients.

The Golf Tournament at Wairakei in April 2016 was a great success and earned Hospice \$18,960 and the auction \$6,700. Jolly Good Fellows chose LTH as their charity of choice for the fourth year running and sincere thanks were given for the whopping \$1,700 which was raised from their St Patrick's Day event. Bunnings had donated lots of lavender which had been picked, stripped, made into gift bags by volunteers, and sold in the shops as gifts. Z Energy's *Good in the Hood* campaign found Taupo Hospice had the most "votes" which resulted in a donation of \$3,119. Also pleasing was the confirmation by the public that Hospice held a great place in the community's heart.

The year saw several valuable and long serving staff members leave Hospice, starting with Denise McKay's resignation in May after six years as Treasurer. She was thanked for doing a wonderful job. Debra Ridgeway was welcomed to the role in August. Wayne Cooper resigned as Retail Manager in August 2016. He had done an amazing job of expanding Hospice's retail operation, including the opening of the Turangi shop, and would be missed. Alison Bowman, Manager of Volunteer Services resigned in September after eight years in the role. Her enthusiasm, energy, hard work and ability to see the funny side of things had been invaluable. Her position was filled in early November by Hilary Morrish Allen, a part-time paramedic based out of Taupo Ambulance Station. There are so many who were involved with Lake Taupo Hospice over the years, all of them dedicated to Hospice.

# **Looking to the Future**

Alan Vane came on board as Chairman in 2014 and has seen many changes over the past five years. Like many organisations such as Hospice, at some point it needed to shift from the pioneer beginnings, which were managed by enthusiastic and dedicated volunteers, to an organisation that is more professionally managed. Lake Taupo Hospice (LTH) volunteers are the core of our organisation but LTH had grown beyond their ability to manage it. The transition to an organisation which is going to be prepared for the future was needed. In that process there has been change and people take change in different ways. There have been the odd hiccups in that process, but LTH now has a stable way forward.

Things do change, especially in the health sector, and sometimes quite rapidly, so what you were planning for often needs to be revisited. Alan felt that the factor driving a lot of strategic planning around hospices in New Zealand is basically the tsunami of old age that is hitting the health system now and will continue to do so through to about 2030/35. It is the current age group that is suffering from multiple chronic illnesses. They live with these illnesses in one form or another until it gets to a point where there is a failure and then hospice comes into play. Therefore, we need to anticipate that the demand on hospice services is going to be significantly higher in the next period of time and then, Alan suspected, it would probably decline.

"The Health System is grappling with that as a whole. It is all very well building hospitals and setting up services, but there is going to be over-resourcing and in New Zealand where we have very limited resources, we need to make our dollars go a long way. I am not sure that we can afford to build a whole range of things that may become redundant in the future."

The Lake Taupo Hospice Strategic Plan tries to anticipate that and be adaptable about the future. LTH doesn't anticipate having an in-patient service but it may do later. The current cost of a hospice in-patient bed, which is 24/7, is over \$1,000 and can vary as high as \$1,500 per night per patient. That is beyond the means of the Taupo community to be able to support by a long way unless we have very significant inflows of money. Currently those are not available.

The Strategic Plan concentrates on community care rather than in-patient care. LTH's strategy is to take the service to the people, rather than the people to us, which is more cost effective for our community. It is going to be challenging for us to get the money to continue the service at current levels but that is the goal that we have given ourselves and we feel it is sustainable. We believe taking it to the community and using technology in consultation is going to be the way forward.

When Alan looked at the statistics across New Zealand, he found that Lake Taupo Hospice has one of the highest numbers of deaths at home compared with other hospices. This is because of the community care model of taking the hospice service to the people. When comparing the utilisation statistics, LTH numbers don't look good compared with some of the other hospices. They have their nurses on site, patients come to see them, and they might see ten patients a day. Our nurses go out to the patients and with travel time, they might see four patients in a day, plus there is a cost to having nurses on the road. That is the difference.

"The other thing which follows on from this is that the money drives everything. In our Strategic Plan there is a recognition that the financial sustainability of Hospice is as important a function as is the provision of care. Therefore, we have employed a dedicated fund-raising manager. Waikato Hospice has a team of five or six people working in their marketing department. We have one. We run our organisation 'really skinny' on the management side. You can't do that with organisations as complex as this Hospice is without things going wrong occasionally. The financial sustainability model that we have aims to build up a capital fund which, when invested, will provide passive income on an ongoing basis. It is dependent on bequests from people and benefactors. Hopefully the wealthy individuals in Taupo will contribute. There are very few large businesses in town that can provide large sums of money. It will take a while for us to build that financial sustainability, but that is our aim."

The retail shops are currently providing most of the LTH funding, but as more op shops open locally, there is more competition amongst the charities. There is a limit on how much funding can be gained from the two shops. There is also a finite amount of money available for charities through grants in New Zealand, as more and more people need to put their hand in the pot to take money out, so there is competition for grants too.

The only other income source is to build up our own fund and or find some other activities which are revenue generated. There is a possibility to open a learning facility in the house at the top of the drive and it could be rented out to other entities to use for learning activities. At the end of the day, it would not be a big enough amount to contribute to financial sustainability.

Hospice NZ is starting to get a lot more assertive with the government about funding. Alan thinks that the elderly should get behind it and be political around their health, especially with the tidal wave of old age coming into the health system. The Minister of Health is cognisant of that and Hospice NZ is becoming more vocal in that conversation. Whether more money will become available is hard to say.

"Obviously, the organisation has expanded which necessitated the move to Izard Hospice House. One thing in the move from the Sunset Street House to Izard House that we didn't anticipate, was a function of the way the building was designed. Having an upstairs and a downstairs was quite disruptive, and we did not envision that at all. Sunset Street was all on the same level which supported an 'all one big happy family' environment. The separate configuration, which coincided with a manager who had a different style to the previous manager caused some disruption. It has taken time to build up that happy environment again."

We are now busy developing a work programme that sets out the detailed activities we will complete under each strategic theme, along with the outcomes and measures that will be used to ensure we are following our agreed path. Many of the initiatives we want to develop require a commitment to collaborate and partner with others. Success therefore will depend not just on us using our own talents creatively, effectively and efficiently, but also on our ability to build strong partnerships, let our supporters also be our advocates, and most importantly, having meaningful relationships with the communities we serve. As a Board and organisation, we are committed to these strategic directions and to creating the right environment in which to carry them out. We can move forward only because of the support we have received from our amazing communities, colleagues, partners and supporters from the past.

Alan Vane, Lake Taupo Hospice Trust

Tēnā koutou katoa, Lake Taupō Hospice Trust has a long and successful history assisting people with illness and in supporting their whanau to "live every moment". From small beginnings in 1983, compassionate people have voluntarily supported and cared for others with life limiting illnesses. In 1993, Lake Taupō Hospice Trust (the 'Trust') was formally incorporated. The trustees over this time to now, have provided support and grown the voluntary services and sought resources through a variety of ways to raise funds for this work. Kaumātua, Ratana and Peehi Wall, engaged with the Trust soon after it was established, thus beginning the long voluntary association of Ngāti Tūwharetoa with the special work of the Trust. Our relationship is strong, valued and continues today. Ratana Wall supported and served the Trust as kaumātua and ensured safety for all cultural protocols and practices and we acknowledge the importance of such leadership on matters that the Trust at times must regularly deal with. 'Te Kapua Whakapipi' is both important and timely to assist the Trust to have clarity of purpose as it charts a new pathway forward in our forever changing landscape, the ultimate outcome being the health and wellbeing of the community that it serves – ko tātou katoa tera. I wholeheartedly commend the work of the Trust in our community and wish it all the best as it moves forward.

Te Ariki te Heuheu Tukino VIII Tumu KNZM