

Lakes  
Adult Palliative Care Service Plan  
2011- 2016

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**Author:** Sharon Hardaker, Midland Cancer Network  
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## List of commonly used abbreviations

|      |   |     |                             |
|------|---|-----|-----------------------------|
| DHB  | District Health Board                     | NGO | Non-government organisation |
| EN   | Enrolled nurse                            | PHO | Primary Health Organisation |
| HCA  | Health care assistant                     | P&F | Planning and Funding        |
| GP   | General practitioner                      | RMO | Resident medical officer    |
| LCP  | Liverpool Care Pathway                    | RN  | Registered nurse            |
| MDT  | Multidisciplinary team                    | TLA | Territorial Local Authority |
| MOH  | Ministry of Health                        |     |                             |
| NASC | Needs Assessment and Service Coordination |     |                             |

## Executive summary

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Palliative care is a concept of care which focuses on relieving suffering and achieving the best possible quality of life for people with a life limiting illness and their family/whānau caregivers. It provides coordinated medical, nursing and allied health services including pastoral care services, delivered where possible in the environment of the person's choice. It includes the provision of grief and bereavement support for families, whānau and carers during the life of the person and following his or her death.

The New Zealand Palliative Care Strategy was launched in February 2001 with the aim of setting in place a systemic and informed approach to the future provision and funding of palliative care services and to ensure that all people who are dying and their family/whānau have access to palliative care services, provided in a coordinated and culturally appropriate way.

The purpose of this plan is to review the current progress of palliative care service development in Lakes District Health Board (DHB) and to identify actions for local palliative care services for the period 2011 to 2016. This will be a living document and will be reviewed and updated as required, particularly when current national palliative care projects are completed and require implementation.

The Lakes DHB has made significant progress in developing palliative care services for its population with a strong focus on community based care and support to allow people to die in their own homes. This has taken some considerable effort and commitment from the DHB and palliative care providers in the community working together. This has also been supported by the availability of additional funding from the Ministry of Health to develop new and existing services.

Through the process of developing this plan some particular strengths have been noted in the current palliative care services within Lakes DHB.

- Implementation of single point of entry & palliative care co-ordination roles of the specialist services in Rotorua and Taupo.
- Demonstrable success in providing home based end of life care – a high proportion of people die at home by comparison to data from Australia and the United Kingdom.
- Good progress in delivering services for local Māori.
- A dedicated palliative care workforce.
- A high level of engagement with primary practice and residential care facilities.
- High level of community support for the current model of care – strong community ownership and support of the specialist palliative care services.

As the Lakes DHB population grows and ages, with an increasing incidence of cancer, a growth in chronic life-threatening disease and people with multiple co-morbidities, and changing family support structures there will be increasing demand for all levels of palliative care services and an increase in the complexity of care.

There has been considerable additional investment by the Ministry of Health in palliative care services (particularly hospices) in the past few years and so it is assumed there is unlikely to be any significant increases (if any) in funding for specialist palliative care services in the foreseeable future. In a financially constrained environment there will be challenges meeting the increasing service demands. The focus for the recommendations in this plan is on service improvement (building on what has already started), improved relationships and building capacity and capability within the generalist level enabling the specialist services to focus on providing education and support for generalists and direct care for people with the most complex needs. A key focus must be on prioritising the allocation of resources and how to organise or deliver services differently to live within the service's means.

There are opportunities identified to work with other palliative care services in Midland to share resources and knowledge, reduce duplication and create consistency across the Midland region. This will form the basis of the regional palliative care workplan.

The palliative care strategic vision is that all people who have a life limiting illness and their family/whānau who could benefit from palliative care have timely access to quality palliative care that is culturally appropriate and provided in a coordinated way. Three long term outcomes are considered necessary to achieve the vision.

- Access to palliative care regardless of setting
- All palliative care providers are configured to ensure a seamless care pathway
- Palliative care provision is high quality.

Each of the long term outcomes have supporting objectives and actions recommended for implementation over the next five years. These have been summarised as:

### Access to palliative care regardless of setting

#### **Ensure sufficient capacity within primary and specialist palliative care**

*Achieving this outcome requires sufficient workforce and appropriate services and infrastructure*

1. Continue to develop the specialist medical palliative care visiting service for Rotorua Hospital and ensure it is fully integrated with the Rotorua community specialist palliative care service.
2. Regularly monitor utilisation and demand for palliative care medical specialist input to palliative care and education in Rotorua and Taupo with the lead provider, and anticipate required changes to meet local population need.
3. Review the composition of specialist palliative care multidisciplinary teams and how the specialist services access allied health support.
4. PHOs to develop and implement sustainable solutions which ensure all palliative people have access to a general practitioner.
5. Develop a workforce plan to address identified areas of skill shortage in palliative care (specialist medical, allied, Māori in palliative care).
6. Ensure access to clinical supervision.
7. Implement the Hospice NZ programme 'Fundamentals of Palliative Care'.
8. Implement cultural competency education for health professionals in specialist palliative care services where required.
9. Develop and implement topic specific education sessions for palliative care health professionals.
10. PHOs to integrate palliative care into patient pathways/guidelines, education and training plans of primary practices.
11. Understand education and support needs for Māori health providers to inform palliative care education planning and service development.
12. Investigate alternative methods of service delivery to create efficiencies and improve access to care.
13. Initiate a project to scope access to grief and loss/bereavement services in Lakes particularly for those people who are not referred to specialist palliative care services.
14. Review access to emergency/out of hour's medication and contribute to the development of a regional standard.
15. Contribute to the development of nationally consistent (or regional, where appropriate) palliative care access criteria, clinical guidelines and other resources where possible, and implement in Lakes where necessary.
16. Lake Taupo Hospice to plan and implement the transition of model of care from shared care with district nursing to hospice community nursing (implementation 1 July 2012). Identify risks and monitor changes to ensure continuity of care for palliative people in the community. Establish KPIs to measure and monitor service change. Undertake evaluation.
17. Plan for relocation of Lake Taupo Hospice specialist services to new site.
18. Work with NASC provider to ensure equity of access to home help, personal care and residential respite/end of life care based on need.

## **Ensure appropriate referrals to specialist palliative care services**

*Achieving this outcome requires awareness of palliative care referral processes and understanding of palliative care principles.*

19. Improve timeliness of referrals by:
  - developing specific written access criteria and referral processes for generalists (including community and hospital based generalists)
  - developing the capability of GPs and hospital services to recognise and refer people to specialist palliative care services on a timely basis
  - reducing barriers to referral through raising public awareness and understanding of palliative care.
20. Develop a Lakes palliative care service directory.
21. Review and strengthen website content of the DHB, hospices, Māori health providers, PHOs and other relevant NGOs.
22. Develop and implement a communication plan for palliative care health promotion.
23. Review and standardise palliative care patient/family/whānau information.
24. Ensure that hospitals and other PHO and NGO services have policies and protocols reflecting the palliative care approach.
25. Educate providers in the palliative care approach through the development of orientation and/or education sessions.

## **Support and align with national palliative care work programme priorities**

26. Apply Resource and Capability Framework to the Lakes district and linking with the Midland region.
27. Implement other national work programme initiatives as they become available i.e. service specifications and any new funding models.
28. Implement the HISO National Specialist Palliative Care Data and Business Process Standard when finalised.

## **All palliative care providers are configured to ensure a seamless care pathway**

### **Ensure there is continuity and coordination of care**

*Achieving this outcome requires integration throughout the health sector and services/providers to be coordinated with each other. This includes the need for*

- *appropriate links between services*
- *appropriate role delineation between providers*
- *shared strategic vision across the region*
- *appropriate information sharing.*

29. Specialist services to strengthen relationships and support to local acute hospital services (also refer to #1).
30. Specialist palliative care services to actively engage with Midlands Health Network and Health Rotorua PHO as they plan and implement primary health changes.
31. Develop and document service level agreements between specialist palliative care services and others.
32. Develop a process to ensure every palliative patient has a nominated care coordinator and there is a plan for continuity of care after hours.
33. Complete the implementation of PalCare into hospices and scope PalCare system integration with (or access by) primary, hospital and other specialist services.

## **Palliative care provision is high quality**

### **Best practice is followed in delivering palliative care**

*Achieving this outcome requires that standards for palliative care services are met; there is an interdisciplinary team approach to palliative care, and patient pathways are followed.*

34. Implement the Hospice New Zealand Standards.
35. Complete implementation of Liverpool Care Pathway (LCP) and monitor utilisation.
36. Implement the LCP reflective data cycle.
37. Encourage and promote research opportunities.

38. Scope and support the implementation of Advance Care Planning with primary and specialist services.

**Palliative care meets the needs of people, their families and whānau**

*Achieving this outcome requires culturally appropriate care, meeting the needs of specific population groups and effective treatments and support.*

39. Carry out a stocktake/hui to understand education and support needs for Māori health providers.
40. Support specialist palliative care services to carry out cultural audits of services.
41. Participate in the development of national or regional clinical guidelines and standards.
42. Develop relationships with other services for support with care of people with nonmalignant conditions, multiple co-morbidities and/or dementia.
43. Scope and explore strategies to improve patient transport between providers.
44. Scope and implement kaupapa palliative care approach including initiatives to support carers to care for their whānau in the community.



## 1. Overview

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### 1.1. Introduction

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The **New Zealand Palliative Care Strategy**<sup>1</sup> was launched in February 2001 with the aim of setting in place a systemic and informed approach to the future provision and funding of palliative care services. The focus of the strategy was on the setting up of services in New Zealand and had a 5 to 10 year vision. Since the strategy was launched considerable progress has been made in the establishment and development of the palliative care services and workforce in New Zealand. The Ministry of Health (MOH) has provided additional funding to support the implementation of the national strategy.

A number of national projects are currently underway that demonstrate progress in achieving the vision and provide clarity in areas identified as requiring further development.

The purpose of this service plan is to review the current progress of palliative care service development in Lakes District Health Board (DHB) and to identify priorities and actions for local palliative care services for the period 2011 to 2016. This will be a living document and will be reviewed and updated as required, particularly as the national palliative care projects are completed and require local implementation.

There has been considerable additional investment by the Ministry of Health in palliative care services (particularly hospices) in the past few years and so it is assumed there is unlikely to be any significant increases (if any) in funding for specialist palliative care services in the foreseeable future. Due to increasing population and demand we expect there will be increased pressure on services. Therefore, a key focus must be on prioritising the allocation of resources and how to organise or deliver services differently to live within the service's means.

The DHB works with other Midland DHBs to advance palliative care services for both the Lakes area and the Midland region as a whole. Activities that can be facilitated by regional cooperation and are of benefit to all DHBs in Midland have been identified and will be included in a regional palliative care overview (separate to this plan).

### 1.2. Service planning process

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This process has included:

- high level review of overarching government palliative care strategies and objectives
- high level review of international trends and priorities in developing palliative care services
- review of previous local palliative service plans
- review of the recommendations from the *Gap Analysis of Specialist Palliative Care in New Zealand*<sup>2</sup>
- analysis of hospice patient demographics and trends from the palliative care monitoring returns
- estimation of some future demand implications from the population projections and what we know about current services
- discussion and consultation with stakeholders about the current model of care and services delivered. Specific sessions were held within:
  - Rotorua
  - Taupo
  - Māori (regional session and some discussion on palliative care at a local hui with Māori providers)
  - Paediatric palliative care (including representatives from Starship Hospital).

The focus of this service plan is adult palliative care services inclusive of malignant and nonmalignant life threatening disease. Currently work is happening at a national level to develop the model of care for paediatric palliative care in New Zealand. A separate paediatric palliative care plan for the Midland region and local networks will be prepared once the national guidance document is received.

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<sup>1</sup> Ministry of Health: *The New Zealand Palliative Care Strategy*, Wellington NZ, February 2001

<sup>2</sup> Ministry of Health: *Gap Analysis of Specialist Palliative Care in New Zealand – Providing a national overview of hospice and hospital-based services*, Wellington, December 2009.

It has been assumed that funding will be limited during this period and it is unlikely there will be any new funding for existing palliative care services from the Ministry of Health.

Implementation of agreed actions contained in the local DHB plans will be the responsibility of the DHBs using their local cancer and/or palliative care forums with programme support from Midland Cancer Network. Implementation of the agreed regional activities and projects will be the responsibility of the Midland Palliative Care Work Group.

## 2. Strategic Context

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### 2.1. Background documents

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The following key documents have been considered alongside the New Zealand Palliative Care Strategy:

- New Zealand Cancer Control Strategy (2003)
- New Zealand Cancer Control Strategy Action Plan 2005-2010 (March 2005)
- Primary Health Care Strategy, February (2001)
- He Korowai Oranga: Māori Health Strategy (2002)
- Health of Older Persons Strategy (2002)
- Report of the Palliative Care Expert Working Group to the Cancer Control Steering Group (February 2003)
- Specialist Palliative Care Service Specifications (Draft 2008)
- Gap Analysis of Specialist Palliative Care in New Zealand (December 2009)
- Positioning Palliative Care in New Zealand (February 2010)
- National Health Needs Assessment for Palliative Care: Phase 1 Report (June 2011)
- Lakes DHB District Strategic Plan Update 2005-2015
- Lakes DHB Annual Plan including Statement of Intent 2011/12 - 2013/14
- Lakes DHB Health Needs Assessment- Summary Report 2008
- Lakes District Palliative Care Services Review July 2002
- Lakes DHB Palliative Project report: Recommendations for Future Service Development. Final report July 2007
- Resource and Capability Framework for Adult Palliative Care Services in New Zealand (Draft Nov 2011)
- Measuring What Matters – Palliative Care (Draft November 2011)
- Palliative Care Workforce Service Review, Health Workforce New Zealand, 2011

### 2.2. Treaty of Waitangi

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The Government and district health boards recognise the Treaty of Waitangi as the founding document of New Zealand and acknowledge the special relationship between Māori and the Crown under the Treaty. Central to the treaty relationship and the acknowledgement of the treaty principles is a common understanding that Māori will have an important role in developing and implementing health strategies for Māori. The relationship must be based on the following principles:

- partnership - Working together with iwi, hapū, whānau and Māori communities to develop strategies for improving the health status of Māori.
- participation - Involving Māori at all levels of the sector, in decision-making, planning, development and delivery of health and disability services that are put in place to improve the health status of Māori.
- protection – Ensuring Māori wellbeing is protected and improved as well as safeguarding Māori cultural concepts, values and practices.

He Korowai Oranga: Māori Health Strategy<sup>3</sup> sets the direction for Māori health development in the health and disability sector. The strategy provides a framework for the public sector to take responsibility for the part it plays in supporting the health status of whānau. The overall aim of He Korowai Oranga is Whānau Ora - Māori families supported to achieve their maximum health and wellbeing. This is an inclusive approach to providing services and opportunities to families across New Zealand. It empowers families as a whole, rather than focusing separately on individual family members and their problems. It requires multiple Government agencies to work together with families rather than separately with individual family members.

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<sup>3</sup> Ministry of Health. 2002. He Korowai Oranga: Māori Health Strategy. Wellington: Ministry of Health  
<http://www.health.govt.nz/publication/he-korowai-oranga-maori-health-strategy>

## 2.3. What is palliative care?

Palliative care is a concept of care, rather than a particular mode of treatment and is not a specialty in isolation. It is a philosophy of care to be owned by the healthcare community as a whole and delivered in all clinical settings.

Palliative care focuses on relieving suffering and achieving the best possible quality of life for people and their family/whānau caregivers. It provides coordinated medical, nursing and allied health services including pastoral care services, delivered where possible in the environment of the person's choice. It includes the provision of grief and bereavement support for families, whānau and carers during the life of the patient and following his or her death.

Palliative care is often not well understood. In some cases it is believed to be just terminal care or end-of-life care, that it is the alternative to life-prolonging or curative care, that it is hospice care, or that it is only available for those that have cancer.

Historically the majority of people accessing specialist palliative care services have had a cancer diagnosis however there is now an increasing recognition of the value of palliative care for people with progressive nonmalignant diseases (such as cardiovascular and cerebrovascular diseases, diseases of the respiratory system, advanced organ failure and degenerative neurological diseases). We are now seeing an increasing trend of people with this wider range of non-malignant diseases also accessing palliative care services.

There is now greater understanding that inclusion of a palliative approach should not be delayed until the end stages of an illness. There is value in a palliative approach alongside curative treatment, particularly to support people with chronic progressive illnesses over many years.

## 2.4. Strategic vision

The national vision for provision of palliative care services as described in the New Zealand Palliative Care Strategy is that:

*All people who are dying and their family/whānau who could benefit from palliative care services have timely access to quality palliative care services that are culturally appropriate and are provided in a coordinated way.*

Underpinning this vision is a community-based model of palliative care services.

Palliative care services are described as providing holistic care – that all aspects of people's needs, physical, psychosocial, spiritual and cultural be taken into account and seen as a whole. From a Māori perspective this is encapsulated in the philosophy 'Te Whare Tapa Wha' (four sided house). This model for wellbeing includes the components Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health), Te Taha Tinana (physical health) and Te Taha Whānau (family health).

## 2.5. Defining palliative care

In 2001, the *New Zealand Palliative Care Strategy* defined palliative care as:

*'the total care of people who are dying from active, progressive diseases or other conditions when curative or disease modifying treatment has come to an end. Palliative care services are generally provided by a multidisciplinary team that works with the person who is dying and their family/whānau.'*

In 2002, the World Health Organisation (WHO) redefined palliative care for adults as:

*'an approach that improves the quality of life of individuals and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'* (World Health Organisation, 2002)

This WHO definition reflects a fundamental shift internationally in recognising that the provision of palliative care is applicable at any stage after diagnosis of a life limiting illness<sup>4</sup>, wherever there is a need and wherever the patient is, and not just at the very end of life (terminal phase).

In 2007, the Palliative Care Subcommittee of the New Zealand Cancer Treatment Working Party further developed the definition resulting in the current working definition of palliative care. This took into consideration the fundamental place of the Treaty of Waitangi, the evolving practice of palliative care, the diversity of cultures, the importance of primary care and the need to integrate specialist and generalist palliative care.

**The New Zealand definition of palliative care** that is now widely referred to is

*Care for people of all ages with a life limiting illness which aims to:*

- 1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.*
- 2. Support the individuals family, whānau and other caregivers where needed, through the illness and after death.*

*Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable when treatments are being given aimed at improving quantity of life.*

*It should be available wherever the person may be.*

*It should be provided by all healthcare professionals, supported where necessary, by specialist palliative care services.*

*Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.<sup>5</sup>*

The definition identifies both generalist and specialist levels of palliative care, which should be part of an integrated framework of care provision. This may be facilitated through local and regional networks with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres and other regional palliative providers.

**Generalist palliative care** is palliative care provided for those affected by life-limiting illness as an integral part of routine standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. This is also sometimes referred to as primary palliative care.

Generalist palliative care is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and aged residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Not all people who have a life limiting illness will need specialist care. Primary health practitioners (usually GPs, practice nurses and district nurses) appropriately care for many people with palliative care needs. These practitioners need to be able to refer and/or seek advice from specialist palliative care services when necessary. For the majority of people this will be for assessment or periodic review with the responsibility for ongoing care remaining with the primary health care provider. For patients with more complex care needs, care will involve a specialist palliative care service in conjunction with the primary health care service. 24 hour/7 day access to specialist palliative care advice, support and consultation is essential to ensure quality care and to build the skills and confidence of the primary health services.

<sup>4</sup> Life limiting illness is used to describe 'illnesses that can be reasonably expected to cause the death of the patient within the foreseeable future. This is inclusive of malignant and non-malignant illness. This differs from chronic illnesses where, even though there may be significant impact on the patients abilities and quality of life, there is less likely to be a less direct relationship between the illness and the person's death'. Palliative Care Australia. (2005). *A Guide to Palliative Care Service Development – a population based approach*.

<sup>5</sup> NZ Cancer Treatment Working Party. *The New Zealand Definition of Palliative Care*;: Wellington 2007  
[www.health.govt.nz/system/files/.../nz-palliative-care-definition-oct07.pdf](http://www.health.govt.nz/system/files/.../nz-palliative-care-definition-oct07.pdf)

**Specialist palliative care** is *palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.*

Specialist palliative care is provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. This is usually by a hospice or hospital-based palliative care team where people have access to at least medical and nursing palliative care specialists.

Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement support. Specialist palliative care provision works in two ways.

1. Directly – to provide direct management and support to people and families/ whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the generalist team. This may be in any of the domains of care: physical, psychological, spiritual, etc.
2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care.

Palliative Care is best delivered through an integrated approach that focuses on the needs of the patient and family/whānau. Such an approach recognises and defines the respective roles of all parties, both specialist and generalist, within a collaborative framework across a given geographical area. An integrated approach can occur in two ways:

**Generalist/specialist integration** – Specialist palliative care services should link with generalist services e.g. general practice, aged residential care, district nursing, Māori providers and hospital teams to ensure that palliative care need is met within a collaborative model that recognises and supports roles and responsibilities of the respective services.

**Specialist/specialist integration** – Depending on the complexity of palliative care need, smaller specialist palliative care services will at times require input from a more comprehensive service with greater specialist resources which may be geographically distant. This could occur on a regional basis with specialist services linking with other DHB specialist services utilising defined linkages and processes.

## Strategies

To support the national vision for provision of palliative care services nine strategies were developed with the aim of building a palliative care culture.

1. Ensure access to essential palliative care services.
2. Each DHB to have at least one local palliative care service.
3. Develop specialist palliative care services.
4. Implement hospital palliative care teams.
5. Develop quality requirements for palliative care services.
6. Inform the public about palliative care services.
7. Develop the palliative care workforce and training.
8. Ensure that recommendations from the Paediatric Review are implemented.
9. Address issues of income support.



## Essential services

Palliative care incorporates a wide range of different services and providers. Care is provided in a variety of settings and requires a case management approach to enable an appropriate combination of interventions by the right providers in the right place, at the right time and based on the needs for each individual and their family/whānau. A full range of essential services ensures access for people to choose the option of dying at home with access to a range of community based services and access to specialist services when required.

Essential services:

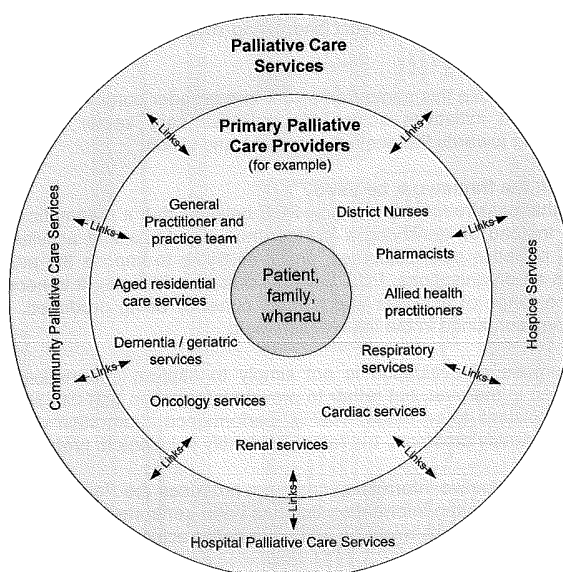
- Assessment – initial and ongoing multidisciplinary team assessment to identify needs early and establish an individualised care plan. General practice services must be included in the multidisciplinary team to ensure continuity of care to the person.
- Care coordination – each person should be allocated a care coordinator. This coordinator is responsible for appropriate information regarding options and services available to the person dying and family/whānau. People need to experience a seamless service with smooth and timely transition from one service to another. Timely referral to palliative care service is essential (preferably not in crisis) with smooth access to inpatient care (respite, symptom control) when required. Rapid and straight forward discharge planning and transfer from acute care to palliative care services is also required.
- Clinical care – access to medical services (primary care and specialist), nursing services and equipment to provide symptom control, 24 hours a day, seven days per week in the community. Access to inpatient care for respite and/or control of symptoms (if required or preferred), bereavement counselling and spiritual care before and after death.
- Support care – support in the home and long term residential care in an appropriate setting for people who are unable to be cared for in the home. Older people currently undergo income and asset testing to access residential care.

To ensure people and their family/whānau have access to the essential palliative care services, a service framework is required with a network of two inter-linked levels of care. The two levels of palliative care services will be local and specialist palliative care services. It is important that where there is more than one provider, services are well coordinated to ensure that the dying person and their family/whānau receive seamless care.

## The palliative care “system”

Cancer Control New Zealand and the Palliative Care Council have developed the following diagram which demonstrates the range of providers of palliative care services and the links between them that tie each together.

**Figure 1: The palliative care “system”**



Source: *Measuring What Matters Palliative Care: Cancer Control New Zealand, February 2012.*

<http://www.cancercontrolnz.govt.nz/pub/measuring-what-matters-palliative-care>

### 3. National palliative care work plan

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In the last ten years, since the development of the New Zealand Palliative Care Strategy, additional Ministry of Health funding has been made available to support the development of both existing and new palliative services. A number of reviews have been conducted to establish the progress made in implementing the Palliative Care Strategy and identifying gaps and areas requiring further work. A summary of these reviews is included in Appendix 1.

A number of national palliative care service development projects are currently under way which are intended to address the gaps and issues identified in previous reviews and to guide sustainable service provision in the future in the face of increasing demand for palliative care services. As these projects are completed, implications for the DHBs in Midland will be considered and this service plan will be reviewed and updated as appropriate. The current projects are outlined below:

#### 3.1. Specialist palliative care service specifications

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In February 2008 the Ministry of Health released a draft service specification for specialist palliative care along with \$2M ongoing funding to help DHBs and hospices implement new components of the service specifications (end of life care, 24/7 telephone advice, education to generalists). After wide consultation it was recognised that further service development work was required before submitting the specifications for final approval. The following work is being undertaken:

- development of a resource and capability framework (role delineation model) for palliative care
- development of a national funding approach.

Based on the need to first complete the above work it is anticipated that the completion of the specialist palliative care service specifications will be delayed until mid 2012. It has been indicated that these might be in a more generic form rather than highly itemised.

#### 3.2. National health needs assessment for palliative care

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The Palliative Care Council of New Zealand recognised the need for a National Health Needs Assessment to determine the need for palliative care in New Zealand on a population basis for all people who would benefit from palliative care. The Phase 1 report: *Assessment of Palliative Care Need* published by Cancer Control New Zealand in June 2011 establishes the number of people who might benefit from palliative care in New Zealand, on both a national and regional basis. Further work will follow which will make an assessment of the services required to meet the identified need and to determine how this compares with current service provision.

#### 3.3. Resource and capability framework (role delineation model)

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It has been recognised that there are currently variations in palliative care structures and levels of service across New Zealand, with access to palliative care services being described as inequitable and inconsistent. The Ministry of Health initiated a project to develop a resource and capability framework for New Zealand which maps out a structure for palliative care services based on the person's assessed need rather than their diagnosis or locality. It is expected to provide clarity for District Health Board funders to determine the level of services they want to purchase to meet the needs of their region, so palliative care providers can plan their service development with guidance on the appropriate workforce and facilities required.

After consultation within the palliative care sector, a draft framework based on a hub and spoke approach has been proposed for final consultation in mid 2012. The draft framework emphasises the targeting of specialist palliative care services to support both those people and family/whānau with the most complex need and generalist/primary providers. This means it is likely there will be an increase in the acuity of people seen by specialist palliative care services, with less complex people cared for by primary care providers.



Once the final framework is known, the impact for Midland will be assessed and a plan for implementation of any agreed changes within Midland will be developed.

Throughout this document we have included (in shaded boxes) some of the key actions recommended in the draft Resource and Capability Framework where they relate to particular issues or needs identified in the Lakes DHB area.

### **3.4. Health Workforce New Zealand palliative care workforce service review**

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Health Workforce New Zealand has recently published the results of a workforce service review to develop a vision and model of palliative care service and workforce for 2020 in a context of increasing demand and limited funding. A key recommendation of the review is the development of eight regional palliative care managed clinical networks, which are linked nationally, to manage palliative care in New Zealand. Recommendations include:

- development of a funding model for community palliative care
- utilisation of advanced nursing roles
- development of the roles of allied health professionals in palliative care.

While it is recommended that one of the eight clinical networks would align with the current Midland DHB grouping of Lakes, Bay of Plenty and Waikato DHBs there could be future implications for service alignment based on the Midland five DHB model (inclusive of Taranaki and Tairāwhiti DHBs) and the recommended eight clinical network groupings.

The recommendations of the workforce service review have not yet been endorsed. It is proposed to test the concept with a demonstration pilot/s in 2012.

### **3.5. National specialist palliative care data definitions and business process**

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The specialist palliative care community in New Zealand has identified the need for nationally endorsed data standards to provide a basis of a common language for discussions between stakeholders and for understanding palliative care in New Zealand.

A draft Business Process Standard and associated Data Definition document were made available for comment during the early part of 2011. These documents are intended to ensure that minimum agreed palliative care data is collected and stored in a consistent manner whenever it is collected and stored. The finalised documents are awaiting approval and release by the Ministry of Health.

### **3.6. Measuring What Matters: Palliative Care**

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The report by Cancer Control New Zealand in 2010 identified a lack of monitoring and evaluation of the Palliative Care Strategy. The Palliative Care Council, in consultation with the Ministry of Health, Hospice New Zealand and with input from other stakeholders, has been working on developing a framework for palliative care that will generate information to inform strategic decision making across all health settings in New Zealand.

A draft document from the Palliative Care Council presents a palliative care outcomes framework using an intervention logic approach (Appendix 2). This has been developed to articulate the desired outcomes and impact of activities across the palliative care sector. We have used the outcomes framework to present the recommendations and actions of this service plan.

### 3.7. Liverpool Care Pathway (LCP)

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The Liverpool Care Pathway for the Dying Patient is an evidence-based, integrated care pathway developed in the UK for the last days and hours of life. The LCP guides health care professionals to deliver best practice care to dying people and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting. The eighteen 'goals of care' in the LCP are measurable and facilitate audit and benchmarking of end-of-life care.

The LCP has been implemented into hospitals, residential care facilities, in the individual's own home/community and into hospices in NZ. It is recognised as a best practice model for care of the dying by the Ministry of Health.

In 2008, additional funding was made available for district health boards to implement 'last days of life care programmes' which has resulted in a significant increase in the use of LCP nationally.

The National LCP Office NZ was established in November 2008 and is funded by the Ministry of Health to coordinate the sustainable implementation of the LCP in NZ. It aims to make significant improvements in the quality and consistency of LCP provision in NZ, including the development of a national database to facilitate benchmarking.

### 3.8. Advance care planning for adults

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Advance care planning (ACP) is a process of discussion and shared planning for future care. It is patient- focussed and includes the health professionals involved in the person's care.

A National Advance Care Planning Cooperative has been formed to facilitate the development and deployment of ACP services in New Zealand. The vision of the cooperative is that *"All people in New Zealand will have access to comprehensive, structured and effective advance care planning."*

A guidance document on ACP in the New Zealand context and a number of supporting publications have been published by the Ministry of Health. While ACP is not palliative care specific, it is not included elsewhere in DHB plans in the Midland region. There is an opportunity with this planning process to consider the implementation of ACP within primary care, aged care, hospice and hospital services. A roll-out plan similar to that implemented for LCP could be considered as a collaborative project within Midland.

Elsewhere in New Zealand (Auckland, Counties Manukau and Wanganui) ACP projects have commenced and will provide additional information to inform an implementation project within Midland.

### 3.9. The Gold Standards Framework (GSF)

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The GSF in use in the UK National Health Service is simply a way of pulling together all the good things that occur in the primary care setting in a way that supports and encourages evidence based best practice. It is concerned with helping people to live well until the end of life and includes care in the final years of life for people with any end stage illness in any setting.

GSF improves the quality, coordination and organisation of care in primary care, care homes and acute hospitals. This enables more people to receive the type of care they want, in their preferred place, with greater cost efficiency through reduced hospitalisation.

The key goals of the framework are to improve:

- teamwork and continuity of care
- advanced planning, including out of hours
- symptom control
- patient, carer and staff support
- benefits identified from implementation of the framework are:
- better assessment and control of symptoms
- more people dying in preferred place of choice

- better planning and fewer crisis calls and admissions through more proactive care
- improved carer support and information
- improved staff confidence, communication and co-working with hospital and specialists

The model has a community palliative care compass that has seven points aiming for better care for people at home in the last years of life.

- Communication
- Coordination of care – nominated coordinator
- Control of symptoms
- Continuity - out of hours and between services
- Continued learning
- Carer support (emotional, practical, bereavement and staff support)
- Care of the dying phase – LCP.

Currently in New Zealand, there is some varied use of concepts of the GSF. While the value of the framework is generally acknowledged there is no widespread implementation into care settings.

### 3.10. Palliative care education and standards

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In 2009, the MOH and Hospice New Zealand considered the results of the national stock-take into service provision. Nationally, there were two areas of need that required focus.

- The need for nationally consistent education programmes that support generalist palliative care providers.
- The need for revised palliative care standards and an ongoing implementation programme to ensure consistency in the quality of service regardless of locality.

Hospice New Zealand coordinated two projects to address the identified needs. Results of the projects were piloted in 2011 and implementation has commenced as follows.

#### **Education**

A *Fundamentals of Palliative Care* learning package has been developed is now released for use by hospices as a part of their education programmes offered to generalists. The initial focus for implementation is gerontology services and residential aged care; however the learning packages will be adapted over the next two years for other settings where a palliative approach is required e.g. general practice, hospital/acute care and district nursing.

The Hospice New Zealand Caregiver Assistant package will be revised and brought into alignment with the Fundamentals programme.

#### **Standards**

New standards for hospice care “*Hospice NZ Standards for providing Palliative Care*” have been developed and are being implemented across New Zealand hospices.

It is anticipated that the standards will be mandatory for member hospices of Hospice New Zealand and will be supported by an audit tool developed by Hospice New Zealand. It is not clear yet how the standards will link with district health board contracts and audit processes and whether the standards should apply to other palliative care providers such as hospitals and residential care.

## 4. Midland region context

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The Midland region includes the Bay of Plenty, Lakes, Taranaki, Tairāwhiti and Waikato DHBs. For many years collaborative activity has occurred amongst the DHBs. To meet service and financial needs and ministerial expectations the DHB chairs and chief executives recognised the need for a more structured and coordinated regional approach to planning and delivery of services. In March 2011 the Midland Regional Cooperation Project commenced with priority given to the implementation of the Regional Clinical Services Plan, coordinating regional clinical networks (including the Midland Cancer Network) and assessing back office and support functions that could be advanced regionally.

The cancer networks are accountable to the DHBs. The geographical boundaries of the regional cancer networks in New Zealand were established on the historical non-surgical cancer treatment flow. Based on this Tairāwhiti and Taranaki currently aligns with the Central Cancer Network, but have an open invitation to the Midland Cancer Network when required. As of 1 August 2011 the Midland Cancer Network now operates from HealthShare, the regional vehicle to drive regionalisation requirements.

A Midland Palliative Care Work Group comprising Lakes, Bay of Plenty and Waikato stakeholders was established in December 2007 as a service specific work group under the umbrella of the Midland Cancer Network<sup>6</sup>. The purpose of the work group is to:

- take a proactive leadership role to oversee the implementation of agreed regional palliative care initiatives for the Midland region
- support and advise the participating organisations about issues, activities and priorities related to the delivery of palliative care services across the Midland region.

The work group membership now has wide representation including primary care, PHOs, hospices, secondary and tertiary hospital service managers, hospital based specialist palliative care, planning and funding and regional Māori Health services. This region wide, all of sector approach has worked successfully to develop palliative care services through the sharing of resources and expertise as well as by using a collaborative approach to address common issues and activities.

It was agreed in December 2009 that a coordinated approach to palliative care service planning would be taken and would incorporate district plans with a regional view.

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<sup>6</sup> Palliative Care (malignant and non-malignant) is part of the Midland Cancer Network work programme.

## 5. Local Lakes District Health Board palliative care

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### 5.1. Lakes DHB strategies

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The **Lakes District Health Board Strategic Plan Update 2005-2015**<sup>7</sup> outlines the priorities for the DHB over the ten year period to 2015. The DHB is committed to working with its communities to:

- achieve continuing improvement in health outcomes and disability support for Māori in the Lakes region
- achieve improvements in the quality of the health services within the region
- reduce inequalities among the Lakes DHB population.

There are three priority areas where palliative care is mentioned specifically.

- Chronic disease states – in particular cancer, which includes the need to continue to implement the NZ Cancer Control Strategy action plan, Midland Regional Non-Surgical Cancer Treatment Services Implementation Plan and the New Zealand Palliative Care Strategy (pg 20)
- Health of older people – where the desire is to extend the palliative care approach to more settings (pg 31)
- Primary health care – recognising the need to work with all providers of palliative care toward an integrated primary care-based approach (pg 39)

The Lakes DHB **Annual Plan including Statement of Intent 2011/12 - 2013/14**<sup>8</sup> provides short and medium term actions and deliverables and associated measures to gauge success. These are aimed at delivering services to meet the Minister of Health's expectations and priorities for District Health Boards and to deliver on national health targets. There are two key areas specific to palliative care services with the requirement to deliver measurable outputs. These are:

- Delivery on regional service plans and, in particular, the Midland Cancer Network initiatives for palliative care (pg 62)
  - Improve access to palliative care services
  - Continue to facilitate implementation of Liverpool Care Pathway
- Older people's health services and rehabilitation and support services aimed to support people to maximise their independence and increase their ability to live in the community. (pg 85/86)
  - More appropriate end of life care
  - Improved care for the person who is dying and their family/whānau- allowing people to be supported and die in their own homes surrounded by family/whānau
  - Older people are able to live longer in their own homes.

This requires generalist palliative care service providers to work within best practice, use of the Liverpool Care Pathway in aged residential care facilities and reduced barriers to access respite funded services and identify alternatives to residential respite care.

Some key themes from the DHBs planning documents are:

- a strategic emphasis on primary and day stay, community, ambulatory care and mental health to manage growth in demand due to population growth and other demographic changes, and therefore reduce pressure to grow secondary service bed numbers.
- to reduce inequalities.

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<sup>7</sup> Available on Lakes DHB website <http://www.lakesdhb.govt.nz/Resource.aspx?ID=7837>

<sup>8</sup> Available on Lakes DHB website <http://www.lakesdhb.govt.nz/Resource.aspx?ID=19481>

## 5.2. Lakes palliative care service reviews

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A health needs assessment conducted by Lakes DHB in 2001 identified significant dissatisfaction within the Lakes community in regard to access to and availability of palliative care services. In response to this a palliative care service review was undertaken in 2002. The report<sup>9</sup> outlined thirty five recommendations to guide service development.

In November 2006 a project was established to examine and briefly describe the range of palliative care services available in the Lakes district. The purpose of the project was to identify any service gaps and/or duplications and make recommendations for future service development. The project reported many of the recommendations of the 2002 review had been implemented, some were no longer relevant and others were included in the recommendations contained in the final report<sup>10</sup>. It was noted that over the previous three years Lakes had made considerable progress in developing the palliative care services for the region.

Achievements of particular note were:

- the development of single point of entry to palliative care services coordinated by the hospices in Rotorua and Taupo
- implementation of care co-ordination as a key function of the hospices
- improvement in the contracting and funding for palliative care with a more equitable split between the Rotorua and Taupo/Turangi areas.
- improvement in the contracting and funding for support services, including residential care services, when these are needed for people who are dying
- the two local PHOs establishment of free GP visits for people within their enrolled population who are dying.

A number of remaining service gaps were identified and nine recommendations for future service development were made in the 2007 final report. These are listed in Appendix 3 along with an assessment of further progress since 2007. At the time, areas relating to adult palliative care that required further work were identified as:

- purchase of palliative physician/specialist services from Waikato DHB and fully integrate with community hospices
- development of written information on palliative care services and how to access them
- PHOs provide information describing palliative services available through general practice and how to access them
- improved access to palliative services in rural areas e.g. additional outreach services, rural home based support workers, increased collaboration of health and disability support providers in rural areas
- education and up-skilling of generalist providers
- building on links with Māori to improve services and access to services for Māori
- clarifying the role of specialist palliative care for people with non-malignant diseases
- improve the provision of palliative care to people in hospital services.

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<sup>9</sup> Lakes District Palliative Care Service Review, July 2012.

<sup>10</sup> Lakes DHB Palliative Project report: *Recommendations for Future Service Development*. Final report July 2007.

## Gap Analysis of Specialist Palliative Care in New Zealand<sup>11</sup>

Between January and June 2009 the Ministry of Health undertook a national stocktake/gap analysis to determine how close hospice and hospital providers of specialist palliative care services, in their current form, were to meeting the new draft service specification for specialist palliative care (2008).

Gaps identified at the time for each of the hospices in Lakes DHB are listed below along with an update of progress. *Note: the gaps identified are based on the responses contained in the palliative care gap analysis questionnaires (2009) completed by hospices and DHB Planning and Funding.*

| Specialist service               | Identified gap (2009)   | Current status and progress made (2012)  |
|----------------------------------|---|--|
| <b>Rotorua Community Hospice</b> | Access to medical specialist resource   | Achieved – visiting service in place   |
|                                  | No apparent appropriately qualified grief and loss resource   | Hospice Clinical Director is a certified counsellor and there is full access to a trained counsellor in cognitive behavioural therapy.   |
|                                  | Provision of a limited number of education courses  | Education is fully underway including the introduction of LCP and Hospice NZ Fundamentals of Palliative Care modules.  |
|                                  | Absence of linkages with palliative care networks and cancer networks for integrated collaborative service planning | Lakes Cancer and Palliative Care Forum now established. Hospice participates in Midland Cancer Network work groups.  |
|                                  | No existing formal patient management system  | PalCare (electronic patient information management system) implemented   |
| <b>Lake Taupo Hospice</b>        | Access to medical specialist resource   | Achieved – visiting service in place   |
|                                  | Clear and specific referral mechanism for children  | To be developed  |
|                                  | No existing formal patient management system  | PalCare (electronic patient information management system) implemented   |
|                                  | Response time not auditable for urgent telephone advice to generalists, and face to face advice                     | To be developed  |
|                                  | Absence of explicit & agreed processes to ensure those with palliative care needs have access to equipment          | Completed for hospice equipment. Some previously identified issues with access to community equipment via Taupo Hospital allied health are being addressed.  |
|                                  | Gaps in home help and personal care services  | Access to home support is available through Lakes NASC short term support funded services. For people with complex long term age or chronic health condition related needs, services are available through Lakes NASC. Taupo Hospice has identified issues with access for some needs – to be addressed at an operational level with the Lakes NASC. |

## Lakes Cancer and Palliative Care Forum

In October 2010, a Lakes Cancer and Palliative Care Forum was formed to take a proactive and quality improvement approach related to cancer and palliative care for the Lakes district. The group meets twice per year, in April and October and is facilitated in a partnership approach between the Lakes DHB and Midland Cancer Network. The group has wide representation of cancer and palliative care clinicians, service managers and primary care, with an open invitation for other interested people to attend.

<sup>11</sup> Ministry of Health, *Gap Analysis of Specialist Palliative Care in New Zealand – Providing a national overview of hospice and hospital-based services*. Wellington, December 2009



### 5.3. Lakes DHB geographic and population demographics

#### Summary

- Approximately 104,000 people live in the Lakes area, about 2.4% of New Zealand's total population (2011 estimate).
- Lakes DHB population is growing at a slower rate than New Zealand population as a whole.
- Between 2011 & 2016 the estimated population growth for Lakes is 1.3% (1,300 people)  
Rotorua + 1% (700 people)  
Taupo + 1.7% (600 people)
- A high proportion of Māori live in the Lakes district (32% compared with 15% in all of NZ). The increase in proportion of Māori in Lakes DHB is predicted to be small.
- The proportion of Asian and Pacific groups is very small and is expected to increase by less than 1% in the 2011/16 period.
- The proportion of people over 65 years is increasing and this will impact on the workload for the palliative care services but the changes are small for Lakes DHB. An estimated 2500 additional people will be in the over 65 age group by 2016 (2% increase from 2011 to 2016).
- There is expected to be an additional 40 deaths per annum by 2016.

The Lakes District Health Board Health Needs Analysis<sup>12</sup> and the Statistics New Zealand 2006 census identify the Lakes DHB population key characteristics. The characteristics that have particular relevance for planning and delivery of palliative care are outlined below. Detailed demographics and population trends are also provided in Appendix 4.

#### Geographic overview

The Lakes DHB area is made up of the Rotorua and Taupo Territorial Local Authorities (TLAs). Rotorua TLA covers an area of 2615 square kilometres and the Taupo TLA covers an area of 6955 square kilometres. The DHB boundary stretches from midway between Mourea and Paengaroa in the north to Mamaku, Mangakino, east of Kurutau in the west down to Mt Ruapehu south of Turangi and to east of Lake Rotoma, and Kaiangaroa Village and Rangitahi on Taupo-Napier road in the east. These boundaries include the major population centres of Rotorua, Taupo, Turangi and Mangakino.

Figure 2: Lakes DHB region map



Note: Rotorua and Taupo hospices are funded by Lakes DHB based on the Territorial Local Authority boundary of the Waikato River and Kaiangaroa Forest roads. An informal arrangement exists between the specialist palliative care services that people will be cared for by the service that most closely aligns with the person's support networks e.g. general practitioner etc.

There are also some inter district flows formally recognised between Lakes and Bay of Plenty DHBs for the Tuhoe area.

<sup>12</sup> Lakes DHB. *An Assessment of Health Needs in the Lakes District Health Board Region: Te Tirohanga Hauora o Lakes*. Summary report 2008.



## Population

The usually resident population in Lakes DHB region from the 2006 Census was 98,319.

Population details by TLA from the 2006 census are:

|                     | <b>Rotorua TLA</b> | <b>Taupo TLA</b> |
|---------------------|--------------------|------------------|
| Population          | 65,901             | 32,418           |
| Māori               | 22,734 (34.5%)     | 8,643 (26.7%)    |
| Pacific             | 2,809 (4.3%)       | 843 (2.6%)       |
| Asian               | 2,733 (4.1%)       | 450 (1.2%)       |
| Median age          | 33.6 yrs           | 37.1 yrs         |
| % > 65 years of age | 11.1%              | 13.6%            |
| % < 15 years of age | 25.3%              | 22.2%            |

*Source: Lakes DHB Annual Plan 23 June 2011.*

Statistics New Zealand (from a 2006 base) estimates the 2011 population of the Rotorua and Taupo districts to be 69,500 and 34,200 respectively making a total population for Lakes DHB just under 104,000.

This is approximately 2.4% of New Zealand's total population. Approximately one third of the Lakes population lives in the Taupo region and two thirds live in the Rotorua region.

In terms of population size, Lakes DHB is 15th largest out of 20 district health boards in New Zealand.

## Population projections

Population growth is a key factor which influences the need for palliative care. Approximately 75% of palliative care patients are aged 65 years or more. Therefore the growth in the population of this age group is an important determinant of need for palliative care.

Statistics NZ indicates an overall population growth in Lakes DHB area of 4% (4,000 people) from 2006 to 2021. The New Zealand population is growing faster than the Lakes DHB population. The New Zealand population is estimated to grow by 15% from 2006 to 2021.

In the five year period of this plan (2011/16) the estimated growth in Lakes is small and is less than the previous five year period.

- Rotorua TLA is estimated to grow by 1% (700 people)
- Taupo TLA is estimated to grow by 1.7% (600 people)
- Overall population growth in Lakes DHB area of 1.3% (1,300 people)

**Table 1: Population projections by Territorial Local Authority (TLA) 2006 to 2021**

| <b>TLA</b>                  | <b>2006</b>    | <b>2011</b>    | <b>2016</b>    | <b>2021</b>    | <b>% Growth<br/>2011 to 2016</b> |
|-----------------------------|----------------|----------------|----------------|----------------|----------------------------------|
| Rotorua                     | 68,100         | 69,200         | 69,900         | 70,100         | 1%                               |
| Taupo                       | 33,400         | 34,400         | 35,000         | 35,400         | 1.7%                             |
| <b>Total Lakes district</b> | <b>101,500</b> | <b>103,600</b> | <b>104,900</b> | <b>105,500</b> | <b>1.3%</b>                      |

*Source: Statistics NZ, Census 2006 Subnational population projections*

For palliative care providers it is important to note that while the increase in the total population is expected to be small, the number of people aged 65 and over and the number of deaths are expected to increase at a higher rate.

## Population projections by age

- By 2021, one in six Rotorua residents will be aged 65+, compared with one in nine in 2006.
- By 2021, one in five Taupo residents will be aged 65+, compared with one in seven in 2006.

In 2016 an estimated additional 1000 people will be aged 65+ in Taupo TLA (2% increase) compared with 2011. Those aged 65 and over will make up 18% of Taupo TLA population compared to 16% in 2011.

In 2016 an estimated additional 1500 people will be aged 65+ in Rotorua TLA (2% increase) compared with 2011. Those aged 65 and over will make up 14% of Rotorua TLA population compared to 12% in 2011.

**Table 2: Spread of population over 65 years and estimated deaths**

|                |      | Population aged under 65 | Population aged 65 & over | % 65 and over | Deaths p.a. | Deaths % change 2011-16 |
|----------------|------|--------------------------|---------------------------|---------------|-------------|-------------------------|
| <b>Taupo</b>   | 2006 | 28,900                   | 4,500                     | 13%           | 230         |                         |
|                | 2011 | 29,100                   | 5,400                     | 16%           | 260         |                         |
|                | 2016 | 28,600                   | 6,400                     | 18%           | 280         | 7.7%                    |
|                | 2021 | 28,000                   | 7,400                     | 21%           | 310         |                         |
| <b>Rotorua</b> | 2006 | 60,500                   | 7,600                     | 11%           | 460         |                         |
|                | 2011 | 60,800                   | 8,400                     | 12%           | 520         |                         |
|                | 2016 | 60,000                   | 9,900                     | 14%           | 540         | 3.8%                    |
|                | 2021 | 58,800                   | 11,300                    | 16%           | 570         |                         |

*Source - Statistics NZ projected population of territorial authority areas 2006 (base) - 2031 update and local population trends*

## Deaths

Between 2011 and 2016:

- Rotorua is estimated to have a 3.8% increase in the number of deaths per annum (520 in 2011 to 540 in 2016)
- Taupo is estimated to have a 7.7% increase in the number of deaths per annum (260 in 2011 to 280 in 2016).

The impact of the increase in deaths will be greater for Taupo than Rotorua. However, the numbers are small - 20 extra deaths p.a. in each TLA - and therefore it is relatively difficult to quantify in terms of impact on resources and revenue/costs for:

- Hospice
- GPs
- Residential care
- Taupo Hospital / Rotorua Hospital

## Ethnicity

In the 2006 census where ethnicity was stated:

- about 32% identified as Māori. This is more than twice the proportion of Māori in the total New Zealand population (15%).
- 3.7% identified as Pacific (NZ = 6.6%)
- 3.3% identified as Asian (NZ = 8.9%)
- About 71% European and other ethnicities

Note: The Census figures include all people who stated each ethnic group, whether as their only ethnic group or as one of several. Where a person reported more than one ethnic group they are counted in each applicable group.

Two main iwi groups (Te Arawa and Ngāti Tuwharetoa) are located within the Lakes DHB area.

**Table 3: Projected population growth by ethnicity**

|                         | <b>Māori</b>  | <b>Pacific</b> | <b>Asian</b> | <b>Other</b>  | <b>Total</b>   |
|-------------------------|---------------|----------------|--------------|---------------|----------------|
| 1996                    | 34,100        | 3,700          | 2,300        | 73,200        | 113,300        |
| 2001                    | 34,100        | 3,800          | 2,700        | 72,600        | 113,200        |
| 2006                    | 34,100        | 4,200          | 3,700        | 74,200        | 116,200        |
| <b>2011</b>             | <b>35,600</b> | <b>4,700</b>   | <b>4,300</b> | <b>75,600</b> | <b>120,200</b> |
| <b>2016</b>             | <b>37,000</b> | <b>5,200</b>   | <b>4,900</b> | <b>76,200</b> | <b>123,300</b> |
| 2021                    | 38,100        | 5,800          | 5,500        | 76,200        | 125,600        |
| <b>% change 2011/16</b> | 3.9%          | 10.6%          | 14.0%        | 0.8%          | 2.6%           |

Source - Statistics NZ sub national ethnic projections 2006 (base) - 2021 update.  
Medium series.

Includes all people identifying in one or more ethnic groups therefore figures exceed population count .

In Lakes overall the proportion who identify as Māori is expected to increase by 3.9% (1400 people) between 2011 and 2016 made up of:

- an additional 1100 people in Rotorua – from 37.3% of the Rotorua population in 2011 to 38.5% in 2016
- an additional 300 people in Taupo – from 28.5% of the Taupo population in 2011 to 28.9% in 2016.

Pacific and Asian:

The Pacific and Asian groups are growing at a faster rate than Māori and others. However they represent only small portions of the overall population.

European and others:

In the 2006 Census around 73% of the total Lakes DHB population identified as European and other ethnicities. This is fairly similar to the proportion for all of New Zealand which was 71% European and other.

In the period from 2011 to 2016, the proportion of European and other in Rotorua is projected to decrease by 0.2% (100 people) and in Taupo is projected to increase by 2.6% (700 people).

### **Socioeconomic status**

New Zealand research has shown that there is a strong association between socioeconomic deprivation and health outcomes. This is measured by the New Zealand Index of Deprivation 2006 (NZDep06). Areas with high NZDep06 scores are associated with poorer health. Deprivation acts as a barrier to accessing health services, and can impact on knowledge of what is available and confidence to seek support upon accessing health services.

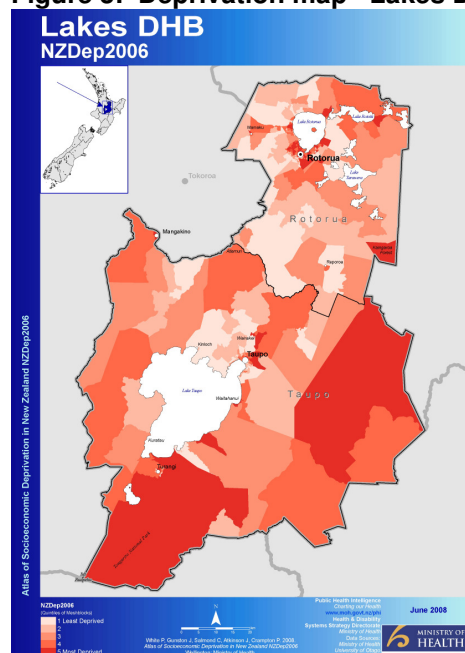
Information shows Lakes to be a 'high inequality' DHB<sup>13</sup>. Estimates for 2010 suggest that more than half (51%) of the population live in areas rated in the bottom two social deprivation quintiles (NZDep06 deciles 7 to 10). However, a much greater proportion of Māori (74%) also reside in these two quintiles.

In the Rotorua TLA the areas with the highest average deprivation are spread through the township, whereas in the Taupo TLA they tend to be on the outskirts of the town and in the more remote rural areas on the western side of Lake Taupo and the south-east area of the region which includes Turangi.

A map showing the deprivation index score for areas within Lakes is shown below. The darkest areas represent areas of very high deprivation.

<sup>13</sup> Lakes DHB Annual Plan 23 June 2011.

**Figure 3: Deprivation map –Lakes DHB**



#### 5.4. Health needs of specific population groups

The DHB takes a population approach to building healthy communities. Different population groups have varying palliative care needs, which require unique interventions to enable appropriate care. This section combines the analysis of the key population characteristics and recommendations from the New Zealand Palliative Care Strategy to consider the requirements for specific groups within Lakes.

##### Māori

As a population group, Māori have on average the poorest health status of any ethnic group in New Zealand. Māori aged 50 and over have higher rates across many health conditions and chronic diseases than non-Māori of the same age group. This includes rates of cancer, diabetes and cardiovascular disease. Of particular concern is that the overall cancer mortality rate for Māori is considerably higher than that of non-Māori. This is not acceptable, and the Government and the Ministry of Health have made it a key priority to reduce the health inequalities that affect Māori.

The New Zealand Palliative Care Strategy emphasised the following.

- Palliative care services are to have policies in place that recognise the specific needs of Māori.
- There are linkages between palliative care providers and Māori development organisations and that a plan for services for local Māori is developed to assist in meeting the specific needs of Māori.
- At a local level, where appropriate, each provider should employ one or more care coordinators who could meet the special needs of Māori, particularly in areas with a high Māori population. The care coordinator would coordinate services and work with the whānau to ensure that the needs of the dying person are met in a culturally appropriate way. The care coordinator could be employed in conjunction with local Māori health providers. It is important that the principles of cultural safety are recognised in the employment of Māori.

2006 Census data shows Lakes has a Māori population more than double national average (Lakes 32%, national average 15%) and within the DHB a high proportion of Māori (74%) reside in the areas where the socioeconomic deprivation is greatest.

The Ministry of Health Mortality and Demographic Data for 2007<sup>14</sup> shows the Māori mortality rate in Lakes to be 1.6 times higher than for the total population in the Lakes region.

<sup>14</sup> Ministry of Health (2010). *Mortality and Demographic Data 2007*

These characteristics provide both opportunities and challenges in the development and delivery of services.

Specialist cultural support services for Māori exist within Rotorua and Taupo Hospitals.

- **Hunga Manaaki** - based at Rotorua Hospital Hunga Manaaki is a service administered by Te Kahui Haoura Trust to provide Māori specialist support to people and their whānau, Māori specialist support to staff, policy advice and support and patient advocacy. Hunga Manaaki ensures Māori values, beliefs and cultural practices are acknowledged and understood as part of the healing process. Hunga Manaaki team represent the person in MDT meetings to ensure care and discharge planning include recommendations and/or findings as per any cultural assessment undertaken.
- **Te Oranga** - based at Taupo Hospital, this service is contracted in from Tuwharetoa Health Services and operationally supervised by the Māori health team. Te Oranga provides advocacy and cultural support for Maori who present to Taupo Hospital and provide staff with cultural guidance within clinical practice when dealing with Māori. Te Oranga represent the person in MDT meetings to ensure the care and discharge planning include recommendations and/or findings as per the Cultural Assessment undertaken by Te Oranga staff.

Lakes DHB also provides funding to other supportive care services where part of their role is to provide support during a palliative stage. Examples include:

- Aroha Mai Cancer Support Group – a Māori based group who support people of all ethnicities who have cancer and their family/whānau through treatment, end of life and after death.
- Rongoa services – traditional Māori healing services which includes people with palliative conditions.

For Māori whānau play an important role in caring for those that are dying at home.

Lake Taupo Hospice has established a close relationship with local Māori. Ngāti Tuwharetoa is represented on the governance board of the hospice and this relationship with local iwi has been significant in the development of the hospice services locally. The hospice palliative care coordinators work closely with the DHB iwi governance committee and have a high level of presence within the local marae. In this region, it is considered the hospice is responding well to the needs of Māori and is delivering services based on Whānau Ora principles.

In Rotorua, the relationship with local Māori is not as strong and there is opportunity to further develop this.

In 2010, the proportion of Māori people receiving care from the hospices was:

- Lake Taupo Hospice: Māori 19%, non-Māori 81%  
(*Taupo TLA population 26.7% Māori – 2006 census*)
- Rotorua Hospice: Māori 30%, non-Māori 70%  
(*Rotorua TLA population 34.5% Māori – 2006 census*)

Hui held with Māori throughout Midland identified some common priorities for Māori. These are summarised as the need for:

- appropriate information available for Māori to raise awareness of palliative care services
- education in palliative care for Māori health providers
- awareness and education sessions targeting specific parts of the community e.g. kaumātua, whānau as carers
- the development of Māori into palliative care careers
- specialist palliative care services to include an understanding of Whānau Ora and Tikanga in relation to palliative and end of life care in their staff orientation and education programmes
- non-Māori palliative care staff to be taught basic Te Reo to enhance communication and understanding between them and Māori people and their family/whānau (especially in the absence of any Māori palliative care staff)
- strategies to support whānau carers to care for their relative in the community.

### People with disabilities and nonmalignant diseases

People with impairments that reduce level of independence will often require more flexible support care and access to aids and equipment to allow them to remain in their home with well supported family.

Traditionally specialist palliative care services have focussed on improving conditions of people who are dying from cancer. Emerging needs of people with other life limiting nonmalignant diseases can benefit from palliative care services. These include:

- cardiovascular conditions such as heart failure, stroke
- end stage renal failure
- chronic respiratory disease
- liver failure
- motor neurone disease
- multiple sclerosis
- HIV/AIDS
- Age related conditions such as increasing frailty, children with life long chronic medical conditions.

These illnesses are often longer in duration than a disease such as cancer and often require a higher complexity of support care. Literature indicates that people with nonmalignant diseases can have improved quality of life through access to palliative care services when required. According to the New Zealand Palliative Care Strategy, 90% of people cared for by hospices in 1998/99 had cancer and 10% had nonmalignant diseases. It was predicted that more people with non-malignant diseases would access palliative care and hospice services.

Data from the hospices in Lakes shows a changing proportion of their patients with a non-cancer diagnosis. Information for 2010<sup>15</sup> shows:

- Rotorua: 69 percent had cancer and 31 percent had other nonmalignant diseases
- Taupo: 63 percent had cancer and 37 percent had other nonmalignant diseases.

Detailed analysis of the reasons has not been carried out but factors contributing to the change could include:

- greater awareness of the role and value of palliative care and hospice services for those with nonmalignant diseases leading to more referrals of these types of people by GPs and hospital specialists etc
- an increased public awareness that hospice services are not just for those with cancer
- an increasing prevalence of non-cancer conditions.

### People in rural areas

Most of the geographical area that is rural and remote falls into the Reporoa/Taupo/Turangi district with many isolated from basic primary health services and required to travel long distances to access specialist secondary or tertiary care. This rural isolation impacts on health providers and professionals ability to service these populations.

People living in rural areas face significant personal costs when needing to be transported to and/or from their home and residential care especially if ambulance transport is required due to the person's condition. The person is charged the full cost of the ambulance transfer which can in some cases be several hundred dollars. From time to time the families choose to use alternative means of transport which can cause significant discomfort for the person and can be particularly unsafe.

Issues also arise for palliative care service delivery to people in remote rural areas. With long distances to travel, few patients can be seen in a day requiring more nurses to support a model of home based care for rural areas. When there is no out of hours GP in an area the ability for community nurses to respond to patient needs out of hours becomes complex, expensive and can be delayed if a visit is required rather than support by phone.

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<sup>15</sup> Measured across all patients who died or were transferred in the calendar year.

### People under the age of 65 years

Local palliative care services and community support services should be able to meet the palliative care needs for people under the age of 65. A small proportion of these people cannot be cared for at home and require longer-term residential care. Aged related residential care services mainly cater for people over 80 and are not always suitable for this younger population group. While short term residential service options may be available, accessing suitable long term out of home care is an issue for this group.

## 5.5. Current Lakes Palliative Care Services

People who are dying can receive services from a wide range of providers as described in Table 4. Access is dependent on the availability of services in each area.

**Table 4: Overview of providers of palliative care**

| Level of Care | Provider  | Type of care  |
|---------------|---|---|
| Generalist*   | Primary care practices - GPs and practice nurses  | Primary care in the community   |
|               | Age related residential care facilities   | Private hospital and rest home level of short and long term residential care  |
|               | District nursing services   | Community (home based) nursing care   |
|               | Public hospital services (e.g. ED, renal, cardiology, oncology)   | Inpatient and outpatient palliative care (non-specialist)   |
|               | DHB allied health staff (e.g. occupational therapists, physiotherapists, social workers)  | Assessment for equipment etc, therapy, access to support services   |
|               | NGOs and volunteer organisations e.g. home support agencies, Māori Health providers, Cancer Society, support groups such as Alzheimer's, Multiple Sclerosis | Information, advice, home and community support care  |
| Specialist*   | Rotorua Community Hospice   | Assessment, care coordination, clinical care, bereavement and grief counselling, family support, day activity programmes and volunteer support                        |
|               | Lake Taupo Hospice  | Assessment, care coordination, bereavement and grief counselling, family support, day activity programmes and volunteer support (plus clinical care from 1 July 2012) |
|               | Waikato DHB Specialist Palliative Care Service  | 24/7 telephone advice for health professionals<br>Visiting medical specialist service   |

**\*Generalist** palliative care providers are any health professionals involved in the care of someone with a life threatening illness, often with no formal training in palliative care. Palliative care is not their primary role or function.

**\*Specialist** palliative care providers are health professionals trained specifically in palliative care working within a multidisciplinary specialist palliative care team.

### Settings

Palliative care occurs in a range of settings and requires a case management approach to enable the appropriate combination of interventions by the right providers in the right place, at the right time and based on the needs for each individual and their family /whānau.

These settings include:

- The person's home (the home of their choosing e.g. own home or family/whānau home)
- residential care facilities
- primary care
  - General practice rooms
  - General practice home visits
  - General practice after hours care facilities
- Rotorua and Taupo hospitals
  - Emergency department
  - Inpatient wards
  - Outpatient services



- Hospice facilities – day programmes
- Māori health provider and marae based services
- other volunteer and supportive care services such as Cancer Society in their facilities or through home visits.

People focussed palliative care coordination is viewed as a key strategy to improving the quality of care to ensure that the patient and family/whānau are supported throughout the continuum of care.

## Generalist palliative care in Lakes

### • Primary health care / general practice teams

For people with a health need the general practice is usually the first and most frequent point of contact with the health service. All palliative people are encouraged to have a GP and the GP remains responsible for their overall care even though they may receive care from a palliative care specialist service.

Most, if not all, GPs will have a number of people requiring palliative care each year. Some people and family/whānau will be adequately supported by the general practice staff and may not require the input of specialist palliative care services. Others may have more complex needs that cannot be met by the GP alone and would benefit from the additional expertise and/or wider support services of the specialist services. In most cases the need for specialist services is likely to be episodic rather than ongoing.

In Lakes DHB, general practice teams refer people to the Rotorua Community Hospice (for Rotorua residents) or Lake Taupo Hospice (for Taupo/Turangi residents) as the single point of access for palliative care coordination and support within each community.

Primary Health Organisations (PHOs) are responsible for organising and delivering primary health care services to meet the needs of their enrolled population. They are funded by the Ministry of Health via DHBs based on the number and characteristics of their enrolled population. There are two PHOs in the Lakes DHB area and approximately 96% of the Lakes population is enrolled with a PHO – see Table 5.

The percentage split between Māori and non Māori of enrolled people is very similar to the makeup of the general population. i.e.

- Rotorua TLA population (estimated 2011) 37.3% are Māori / 37.4% of the enrolled PHO population are Māori.
- Taupo TLA population (estimated 2011) 28.5% are Māori / 26.6% of the enrolled PHO population are Māori

**Table 5: PHOs in Lakes and enrolled population as at Quarter 1, 2012**

| PHO   | PHO Enrolled Population             |               |       |               |       |            |      |
|---|-------------------------------------|---------------|-------|---------------|-------|------------|------|
|   | Total enrolled (Lakes DHB domicile) | Māori         | %     | Non Māori     | %     | Not stated | %    |
| Health Rotorua Ltd (HRPHO) <sup>16</sup>              | 67,087                              | 25,106        | 37.4% | 41,461        | 61.8% | 520        | 0.7% |
| Midlands Health Network (Taupo/Turangi) <sup>17</sup> | 33,269                              | 8,855         | 26.6% | 24,190        | 72.7% | 224        | 0.7% |
| <b>Total</b>  | <b>100,356</b>                      | <b>33,961</b> |       | <b>65,651</b> |       | <b>745</b> |      |

Source: Ministry of Health PHO Enrolment Demographics 2012 Qtr1 (Jan – March 2012)

<http://www.health.govt.nz/our-work/primary-health-care/about-primary-health-organisations/enrolment-primary-health-organisation> Accessed 29.02.2012

There is no specific categorisation or reporting of palliative care work undertaken by PHOs or general practices and therefore this component of work of primary practice cannot be quantified.

A challenge for GPs is the difficulty maintaining up-to-date knowledge and skills in caring for palliative people when they may only care for a few people with palliative needs each year. The need for specialist palliative care services to give advice and support to GPs, to provide on-going education opportunities and to develop tools, clinical guidelines and quick reference information for GPs is a critical role for the specialist services.

Discussions with stakeholders indicated there are no issues with access to GPs in the Rotorua district, including access out of hours. It was reported that GPs and the hospice nurses plan care and work very

<sup>16</sup> Health Rotorua Ltd (HRPHO) is the sole primary health organisation for the Rotorua and Murupara districts. Total enrolled population is 71,381 but some are domicile in DHBs other than Lakes.

<sup>17</sup> Three Practices in Taupo and one in Turangi.

well together. While locums often work in general practices they seem well informed of palliative patients and processes. On occasions palliative people present at the Rotorua hospital emergency department. When this happens the Hospice is usually contacted and works with ED staff to address the person's needs, often enabling them to return home.

In the wider Taupo/Turangi district there is a mixed level of engagement of GPs in providing palliative care. Many GPs consider it to be an integral and valuable part of their work. Some prefer not to provide palliative care or end of life care. The varied level of commitment by GPs to providing comprehensive palliative care, including being available after hours, and willingness to do home visits or visits to people in residential care is of significant concern.

The availability of general practice services are being impacted on by the difficulties to recruit and retain GPs, this is particularly evident in remote/rural areas where there is little collegial support and the responsibility for out of hours call is high. This contributes to the reduced GP services out of hours, a higher turnover of GPs and increased use of locums unfamiliar with local support services and processes. In turn, this can impact on local palliative care services required to coordinate and provide care for palliative people.

Taupo Hospital provides after hours GP care from 2200 to 0800 hours (i.e. individual GP's/practices are not required to provide after hours services during these hours). However, A&E centres or access to the hospital emergency department does not always suit the requirements of palliative patients as many are not ambulatory and need to be visited at home. Feedback from Hospice indicates the lack of GP services/responsiveness to do home visits after hours increases the reliance on district nursing and hospice nurses out of hours, and potentially for emergency services such as the ambulance service (although this has not been quantified at this time). There seems to be a lack of clarity around the provision of care after hours. It is especially important for palliative patients that they, and their family/whānau, know what to do when an urgent issue arises out of hours.

In general, the method of funding general practice visits is not conducive to providing palliative care. The length of time given for a routine GP appointment is insufficient for providing a quality palliative care service which requires considerably more time to be spent talking with the person and family/whānau. Many GPs are reluctant to charge the person for the cost of the extended consultation and, in many cases the patient could not afford to pay the actual cost.

In response Health Rotorua PHO and Midlands Health Network both have Ministry of Health funded SIA programmes<sup>18</sup> to enable the general practice team to provide support, including home visits, to people who are in end stage of a disease and are unable to attend the surgery. While these programmes are very useful in improving access GP services for palliative people there are weaknesses:

- The patients' GP has to be a member of the participating PHO (the Mangakino general practice has transferred to the National Māori PHO Coalition and patients may not gain access to SIA funded services)
- SIA funding covers only those people enrolled with a PHO (enrolment is patient choice)
- Criteria for access and level of subsidy/funding between the PHOs are different.

Alternative palliative care funding schemes are being used elsewhere in New Zealand such as the MidCentral DHB Palliative Care Partnership. This is an example of palliative care primary and secondary integration which provides an alternative funding scheme which aims to reduce the barriers to primary health care for palliative people.

In response to the growing demand for primary health services with an increase in older population, a decreasing health workforce and the government's call for change the Midlands Health Network proposal under the governments *Better, Sooner, More Convenient* primary health care initiative was successful. This initiative aims to deliver a more personalised primary health care system that provides services closer to home and makes Kiwis healthier. It acknowledges that primary health care has a part to play in helping reduce acute demand pressure on hospitals by better managing chronic conditions and proactively supporting high need populations.

A package of services is proposed to make significant improvements. This includes multiple Integrated

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<sup>18</sup> SIA - Services to Improve Access funding. For more details refer to Appendix 7

Family Health Centres, nurses acting as case managers for people with chronic conditions, providing a wider range of care and support for people and shifting some secondary care services to primary care.

While palliative care is not one of the current identified priority areas of Midlands Health Network the initiatives focussing on chronic diseases, health of older people services, extended/after hours services and implementation of integrated family health centres have the potential to provide improvements in palliative care in the Taupo/Turangi area where primary practices are a part of the Midlands Health Network. In particular, the concept of integrated health centres could result in closer involvement of hospice nurses in the primary care team.

- **Community (home based) care**

Flexible home based care is required for people to be able to choose to die at home and for the person and family/whānau to be well supported during this time.

### ***Nursing***

Historically there have been three primary palliative care nursing service delivery models in Lakes. These developed to address the different demographic characteristics of the Rotorua and Taupo districts.

- ***Rotorua***

Rotorua Community Hospice Trust provides a package of home based palliative care services for all people living in Rotorua. The Hospice delivers the primary palliative nursing functions as well as access to the multidisciplinary team and services of the hospice.

Rotorua District Nursing Service provides access to continence advice, continence products if required prior to the person needing palliative care, stoma therapy, oxygen therapy and complex wound management.

- ***Taupo***

Lake Taupo Hospice provides the assessment and palliative care coordination, access to palliative medical specialist as a specialist palliative care provider, whereas the Lakes DHB district nursing service provides the primary palliative clinical nursing care and a 24/7 response service. The smaller population in this area and associated level of funding available for palliative care services has required both nursing teams to work closely to ensure the person's needs are met.

However, with increased demand for more intensive clinical interventions to support people to remain out of hospital, the Taupo district nursing service has required to reconsider its nursing service delivery model. From 1 July 2012, Lake Taupo Hospice nursing team will provide all home based palliative care services for the area at all times.

Two Midlands Health Network nurse practitioners are employed in Turangi and Mangakino. The purpose of these roles is to improve care for people with high needs and chronic conditions living in isolated rural areas. These nurses work closely with hospice services when there is a palliative person in their area. This arrangement works well.

- ***Reporoa***

The rural area between Rotorua and Taupo is covered by Health Reporoa nursing service who provide generalist palliative care service and work closely with both specialist palliative care services for people within the Kaiangaroa, Ngakuru, Reporoa area.

### ***Home and community support services***

Where people have been assessed and are receiving MOH, ACC or DHB funded home support, these funded services do not cease when a person requires palliative care services. If as a result of the palliative condition the person requires additional support, this is available in different ways throughout the district.

A priority is that people are appropriately assessed and not subjected to additional unnecessary assessments by other organisations. Service packages are expected to be flexible and cover multiple visits per day and up to seven days a week based on assessed need.

MOH/DHB criteria for home help services requires a person to have a Community Services Card and excludes where this work can be undertaken by family/whānau or people who are living in the house. There is no requirement to have a Community Services Card for a person the receive personal care.

While the access to these services is similar throughout the district there are some differences in the processes.

- **Rotorua**

The need for home support is assessed by Rotorua Hospice nurses in conjunction with the family/whānau and support with personal care is provided by Rotorua Hospice using RNs and HCAs. Access to home help can be covered by the Ministry of Social Development (MSD) or as part of short term support services available through the Lakes Needs Assessment Service Coordination (NASC)<sup>19</sup>.

Rotorua Community Hospice is funded to cover the cost of personal care. No issues are reported with home support/personal care services in Rotorua.

- **Taupo**

Access to funding for home help and personal care is via the Lakes NASC. The Lake Taupo Hospice team assess the person's need and advise the Lakes NASC the level of support required. The DHB has agreements with five home based support providers in Taupo/Turangi and the client may choose which provider. Lake Taupo Hospice has developed a close relationship with two of these providers (Tuwharetoa Health Services and Health Care NZ) and supports the ongoing education and training of support workers to meet the needs of palliative services. The hospice team is also responsible for reassessing the person's needs over time and adjusting service packages to meet those needs.

A specific funding stream is available to cover the cost of short term home based and residential palliative care. Where the service may be required longer, access is possible through other funding streams, such as age related, long term support - chronic health conditions. Lakes NASC manages the payment process to providers.

When services have been in place under a specific short term funding stream for more than six months, consideration is given to changing to a long term funding stream. For people under 65 this may require application to the Long Term Support - Chronic Health Conditions team which is for people who have high and complex needs on a daily basis. The approval process is intensive and acceptance is based on national/regional criteria.

Some examples of issues were identified for people needing home support which indicates there is a need to review whether the criteria is being applied in practice as intended across the Lakes district. In particular, this includes meeting assessed needs of those aged under 65 years.

It is noted that service quality depends on the quality and education level of the HCAs employed by contracted services in Taupo (unlike Rotorua where HCAs are employed directly by the hospice).

The New Zealand Palliative Care Strategy defines the set of essential services that dying people and their families/whānau should have access to including 'Support Care based on need'. Support care includes support in the home. The draft Resource and Capability Framework states as one of the principles underpinning the framework "Palliative care services will be provided according to need in a seamless manner, regardless of setting, diagnosis or location".

<sup>19</sup> The NASC undertakes assessments and coordinates care for people who have loss of independent function that requires support due to personal health, mental health, short term health condition following acute event or palliative need and long term age related conditions.

The hospices work closely with Māori health providers in the DHB district and work directly with family and whānau to educate them on the role they have as the in-home carer and support.

Considerable effort has been made by Lakes DHB and the hospices to put in place resources to support palliative people who are dying to remain in the community (e.g. at home or in residential care). This has been further enhanced by the introduction of the end of life Liverpool Care Pathway (LCP) to guide the care of people in their last days of life. One of the aims of the LCP is to avoid unnecessary hospital admissions by anticipating and planning for the possible needs of palliative people who are dying, usually resulting in them being able to remain at home.

- **Residential care**

There are 14 MOH certificated and DHB contracted age related residential care facilities in Lakes providing services of different levels. Table 6 shows the service type and capacity at each facility.

**Table 6: Lakes residential care beds**

| Facility                                       | Number of beds in each service level |                          |                  |                       |                   |
|--|--------------------------------------|--------------------------|------------------|-----------------------|-------------------|
|  | Rest Home                            | Specialist Dementia Unit | Private Hospital | Psycho-geriatric Unit | TOTAL in facility |
| <b>Rotorua</b>                                 |                                      |                          |                  |                       |                   |
| Ascend Quality Care                            | 26                                   |                          |                  |                       |                   |
| Bupa Care Services (GHC) Ltd at Redwood        | 19                                   | 20                       | 22               | 6                     | 67                |
| Bupa Care Services (GHC) Ltd at The Gardens    | 31                                   |                          | 31               |                       | 62                |
| Cantabria Home & Hospital                      | 151                                  | 12                       | 95               |                       | 258               |
| Fergusson Home                                 | 31                                   |                          |                  |                       | 31                |
| Glenbrae Rest Home and Hospital                | 31                                   |                          | 10               |                       | 41                |
| Lara Lodge Rest Home                           | 24                                   |                          |                  |                       | 24                |
| Whare Aroha Home & Hospital                    | 21                                   | 21                       | 36               |                       | 78                |
|  |                                      |                          |                  |                       |                   |
| <b>Taupo</b>                                   |                                      |                          |                  |                       |                   |
| Bupa Care Services (GHC) Ltd at Liston Heights | 32                                   | 12                       | 32               |                       | 76                |
| Lennox Cottage                                 | 15                                   |                          |                  |                       | 15                |
| Monte Vista Resthome & Hospital                | 26                                   |                          | 15               |                       | 41                |
| Oceania - St Johns Wood Trust                  | 31                                   |                          | 19               |                       | 50                |
| Oceania - Wharerangi                           | 12                                   | 20                       | 15               |                       | 47                |
| Summerset by the Lake                          | 12                                   |                          |                  |                       | 12                |

Source: Lakes DHB Planning and Funding- updated as at April 2012

Residential care facilities carry much of the burden of caring for dying people. For many people the residential care facility is their home – they are essentially there until they die. Many die in a rest home or private hospital without the need for specialist palliative care input. Information on the total number of deaths in these facilities has not been located for inclusion in this plan.

Rest homes generally provide care for frail, elderly people using health care assistants with some registered nursing oversight and care planning. Private hospitals cover medical and geriatric care, and predominantly care for the frail elderly who need more frequent access to registered nurses with most care provided by both registered nurses and health care assistants.

Dementia and Psychogeriatric units are specific for people who have behaviour and psychological symptoms of dementia and require a secure environment. Meeting the palliative care needs of this group of people requires specialist attention.

The Australian Productivity Commission's report<sup>20</sup> suggests palliative and end of life care should be core business for aged care services yet in practice the quality of care is variable and residents are often transferred to hospital when the needs are beyond the resources of residential care staff. The specialist palliative care services have an important role to play in supporting staff who are predominantly caregivers rather than registered or enrolled nurses, to deliver effective palliative care.<sup>21</sup>

Good relationships exist between the Rotorua and Lake Taupo Hospice nursing teams and the age related residential care facilities. There is a genuine willingness by residential care homes in Lakes to provide a high standard of care for residents and an interest in developing the skills and knowledge of staff. Releasing large numbers of staff for education sessions on a regular basis can be difficult. In Lakes, the use of agency staff is low and the staff turnover within this industry has settled over the years.

The Liverpool Care Pathway for care of the dying patient is being progressively implemented into those residential care facilities in Lakes who provide end of life care. The education component of LCP and use of the pathway is seen as having a very positive influence on the delivery of end of life care for residents.

Accessing suitable long term inpatient or residential care can be an issue for palliative people under 65 years of age. In the lakes district there are currently no other options available to this group of people other than transferring to an age related residential care facility where the focus is more on support for very old and frail people. Residential care facilities are based in Rotorua or Taupo meaning people living in more rural areas need to transfer to another town. Long term care is not provided by Rotorua or Taupo Hospitals. This issue is not unique to Lakes DHB.

People under the age of 65 years make up about one third of hospice patients (n=25 Taupo/52 Rotorua) and will include a number of people who would be considered as having high and complex chronic health needs, similar to older people or who are Māori and have an 8 to 10 year shorter life expectancy. The numbers of palliative people in Lakes likely to have the need for age appropriate long term residential care are small and could be from anywhere in the DHB area. Therefore, most cases will require a solution based on individual circumstances. For people under 65 yrs, it will need to be identified early as a part of the care plan what the options might be should the need arise. Referral pathways will need to be identified as well as what financial or other support would be available.

Both hospices have access to residential care facilities to access beds for symptom management or respite. It is unknown if there is any impact on acute admissions to Lakes DHB hospitals because of access issues relating to short term residential care services.

As the population and the proportion of those aged 65+ increases, there will be additional demand for residential care services for palliative people. Analysis of likely increased demand and capacity requirements will be linked with the DHB planning of future aged residential care services. This work indicates that current capacity in this sector is sufficient until 2018.

In both Rotorua and Taupo, people who need respite or end of life care go to any of the aged care facilities, usually those with hospital level care, depending on client choice and where there is a vacancy. The current occupancy levels in residential care are around 75% and the providers who offer a range of care are certified to provide a range of service which is not related to specific "beds" therefore they are not restricted to where to place people with palliative care needs as long as the service needed is provided when required.

In Lakes the demand for short term respite care beds for hospice patients is low as normally respite is provided in the home using hospice staff and volunteers.

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<sup>20</sup> <http://www.pm.gov.au/press-office/productivity-commissions-final-report-disability-care-and-support>

<sup>21</sup> Hall B. *Resource and Capability Framework for Adult Palliative Care Services in New Zealand* – Draft for consultation, November 2011.



- **Local hospitals**

There are two acute general hospitals in Lakes DHB:

- Rotorua Hospital has 178 inpatient beds & 22 day stay beds
- Taupo Hospital has 10 beds (with contingency to increase to 20 if the need arises).

Generalist palliative care is provided in hospitals by general ward staff, as well as disease specific teams for instance oncology, respiratory, renal and cardiac teams who provide care for people who are dying as a result of their illness.

The acute hospitals do not have dedicated inpatient palliative care beds. Palliative people requiring hospital care for an acute episode of illness, complex symptom control and/or interventions are admitted to Rotorua or Taupo Hospital either as a planned admission or by presentation at the emergency department.

There have been no major issues reported in accessing beds in Rotorua Hospital when required. Rotorua Hospice staff have developed links with Rotorua Hospital services and this relationship is evolving, in particular since the introduction of the cancer nurse specialists at Rotorua Hospital and the visiting palliative medicine specialist service from Waikato.

In 2011 the number of beds commissioned in Taupo Hospital was reduced to 10, with contingency to go to 20 to meet changing demands, particularly seasonal variations. Beds in the hospital are managed using CapPlan<sup>22</sup>. There is some concern of the impact for district nursing and hospice nurses if there is difficulty accessing beds in Taupo Hospital for acutely ill people. There is the potential for the community based services to have an increase in demand and/or complexity of care due to lack of beds and/or early discharge from hospital. This needs to be monitored to determine if timely access to the hospital for palliative people is an issue and any identified issues discussed between the hospice and hospital.

Hospice nurses attend hospital MDT meetings and work with the relevant services of the local hospitals to provide specialist support for palliative people admitted to hospital and ensure there is appropriate post discharge support.

- **Allied health services**

Allied health services including pharmacy, physiotherapy, occupational therapy, speech language therapy and social work provide valuable assessment and support for palliative people.

Both hospices have trained counsellors as a part of their workforce and Lake Taupo Hospice has employed a part time social worker. However, it is noted that the specialist palliative care services do not have other allied health professions e.g. occupational therapy, physiotherapy and speech language therapy as a part of their multidisciplinary teams. Input or assessment required by other allied professions is accessed via the DHB services.

- There were no access issues reported for Rotorua palliative people.
- Taupo Hospice perceives issues with:
  - referral wait times for allied health services via Taupo Hospital (occupational therapy, physiotherapy)
  - a lack of community equipment
  - no capacity for community referrals to the DHB social worker unless the person is an inpatient of the hospital (*therefore this has lead to Taupo Hospice directly employing a part time social worker from late 2011*).

The DHB allied services (Occupational Therapy in particular) are not aware of the reported operational issues. At the time of developing this report the relevant hospice and hospital allied staff have not met to discuss the issues. It is suggested that a joint meeting/s to resolve this and develop process agreements should take place as soon as possible.

The hospices have well developed relationships with community pharmacies. Access to medication out of hours has improved since LCP with pre-emptive prescribing was introduced. In general, access to

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<sup>22</sup> CapPlan is a capacity planning and forecasting solution for healthcare organisations. It is used to make daily decisions about hospital capacity, plan beds and match occupancy and nursing resource.



medication in the city areas is not an issue. However, during a stakeholder meeting it was reported that occasionally district nurses in Taupo would access medication from the hospital ward if needed (often because families have forgotten to collect medication during business hours). There should be some discussion and arrangement of what to do in these circumstances when the palliative nursing model changes from district nursing to hospice in July 2012. The availability of emergency medication kits at Taupo Hospital that could be accessed by hospice nurses may be an option rather than using ward stocks (if warranted depending on the number of occasions this is expected to occur).

An issue exists for those people living in Turangi and the surrounding area. Access to medication after hours is difficult because there is no resthome, no GP after hours clinic or after hours pharmacy. Solutions such as a locked box at the residence will need to be explored for people living in remote areas. (This issue is not unique to Taupo).

It should be noted that the lack of allied professions as a part of the hospice teams is not unique to Lakes. Allied health professions are commonly part of palliative care multidisciplinary teams in other countries but their role in palliative care teams in New Zealand is under developed. In general, in New Zealand, they are part of DHB allied health teams with competing service demands. The ability for allied professionals to develop expertise in palliative care is limited. There is a nationally recognised lack of formal training in palliative care for allied health professions and limited access to funding to support further training/education.

## Specialist palliative care

Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement support.

- **Services**

The DHB contracts two hospices for the provision of specialist palliative care.

- Rotorua Community Hospice for services in Rotorua territorial local authority.
- Lake Taupo Hospice for services in Taupo territorial local authority.

The DHB has a contract with the Waikato DHB specialist palliative care medical team from Waikato to provide a 24/7 telephone advice service which can be accessed by generalist medical staff in the district (GPs and hospital doctors) as well as hospice nursing staff.

The hospices provide a single point of entry for referrals for specialist palliative care in each of their districts and coordinate care to ensure their people and family/whānau have access to the services they require.

Support, advice, education and training for generalists are key responsibilities of the specialist palliative care service.

Both hospices contract a visiting palliative medicine specialist from Waikato DHB to provide a monthly medical specialist clinic for consultations and where necessary home visits, as well as support and education for GPs and hospital medical staff. These services are relatively new and with time the relationship between the hospitals and community palliative care will continue to strengthen and opportunities to provide additional palliative care education and support for complex palliative care in the hospital setting will continue to develop.

Service profile summaries and patient demographics for Lake Taupo Hospice and Rotorua Community Hospice are provided in Appendices 5 and 6.

- **Access criteria and clinical guidelines**

The access criteria for both hospices is:

*Any person with active progressive life limiting disease (cancer and non-cancer) that is unresponsive to treatment and who could reasonably be expected to be in their last year of life.*

Acceptance of referral into the service is determined following a comprehensive assessment.

The draft Resource and Capability Framework recommends the development and adoption of national eligibility criteria for access to specialist palliative care services.

Clinical guidelines are generally available within the hospices for the services they provide. Lake Taupo Hospice uses and promotes the use of the Waikato Palliative Care Clinical Guidelines<sup>23</sup> by generalists. These clinical guidelines also need to be promoted to generalists in Rotorua.

The draft Resource and Capability Framework recommends the adoption of national evidence based symptom management guidelines to reduce duplication and resource required for review.

Referral criteria and processes seem to be well known by GPs within the districts however issues have been reported with late referral to the specialist palliative care services, particularly in Rotorua (further explained in section 7.1 Stakeholder Feedback).

- **Accreditation and audits**

The Hospices undergo HealthShare regular three yearly audits against the Lakes DHB contract. Lake Taupo Hospice participates in the QPS Benchmarking Programme (participation is voluntary) and is a pilot site for the Hospice New Zealand Standards.

<sup>23</sup> Available from this weblink [Palliative Care Guidelines - Waikato District Health Board](http://www.waikatodhb.govt.nz) or follow [www.waikatodhb.govt.nz](http://www.waikatodhb.govt.nz) > Health professionals > Primary Care management guidelines > Palliative Care Guidelines

- **End of life Liverpool Care Pathway for the dying patient (LCP)**

It is widely said that most people, given a choice, would prefer to die at home. In order to support this it is essential to provide comprehensive palliative care services within the community.

Considerable effort has been made to put resources in place to support people who are dying to remain at home or in residential care. This has been further enhanced by the introduction of the LCP to guide the care of people in their last days of life. The LCP is an integrated care pathway that guides healthcare professionals to deliver evidence-based best practice care to dying people and their families in the last days and hours of life, irrespective of diagnosis or care setting and has been endorsed by the Ministry of Health as the End of Life Care Pathway for use in New Zealand.

One of the aims of the LCP is to avoid unnecessary hospital admissions by anticipating and planning for the possible needs of palliative people who are dying, usually resulting in them being able to remain at home.

Lake Taupo Hospice is the lead facilitator for implementation of the LCP in the Taupo/Turangi district. A pilot project commenced in November 2008 with the aim of implementing the LCP into Taupo aged care facilities, general practices, Taupo Hospice, hospital and the district nursing services in Taupo/Turangi. The roll out of LCP to these groups has been completed with a total of eight registered sites. This was supported by the appointment of dedicated resource as an LCP facilitator/coordinator (50% DHB funding and 50% community funding). This facilitation role is important to ensure the continued sustainability of LCP in the region. The network nurses group is in place, users are transitioning from version 11 to version 12 of the LCP document and use of the reflective data cycle (the continuous quality improvement tool and process for LCP) is commencing.

Rotorua Hospice is the lead facilitator for implementation of the LCP in the Rotorua district. A pilot project to implement LCP in 2 sites - one residential care facility and the medical unit of Rotorua Hospital – commenced in March 2010 with funding from a Ministry of Health Service Development grant. Implementation into the pilot sites has been completed and a further four residential care sites and the hospice community team have been added for rollout during 2012.

- **Information management**

There are a range of services contributing to the care of palliative people (hospital, hospice, GPs, district nursing, home and community support services, NASC, allied health, pharmacy etc). Each service maintains their own information and patient records and there is little, if any, integration of systems and limited sharing of information. Obtaining information for this plan has been difficult because the information is either manually held, fragmented or simply not available.

The availability of complete patient information, quickly and accurately, is extremely important to the effective relationships between primary/generalist and specialist services, and it enhances seamless care between providers.

The hospices in Lakes have historically used a combination of paper based and Excel spreadsheet records. This means information management has been very manual, labour intensive and prone to error. Waipuna Hospice has recently led a project with the Midland hospices<sup>24</sup> to purchase and implement PalCare an electronic patient information management solution for the delivery of palliative care and support services at the point of care. This has been made possible by community grant funding for both software licences and communications equipment.

In addition to the benefits of shared patient information, PalCare makes a wide range of other business related activities of the hospices such as monitoring and reporting more accurate and efficient.

The implementation of PalCare in the Midland hospices is currently in progress and will follow a staged roll out. Phase one (2011/12) is implementation within the hospices with some capability for GPs to access information via web access. Phase two will expand access to a wider group such as primary, hospital and other specialist services and will explore the integration with other systems.

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<sup>24</sup> There are five hospices in the Midland area - Waipuna Hospice, Hospice Eastern Bay of Plenty, Hospice Waikato, Rotorua Community Hospice and Lake Taupo Hospice

There will be a requirement for DHBs and hospices to implement the HISO National Specialist Palliative Care Data and Business Process Standards when finalised.

Consideration also needs to be given to PalCare's interface with the regional data repository which is a wider Midland DHB regional information systems project.

The draft Resource and Capability Framework identifies several enablers of care across all services to facilitate the integration of care. This includes an integrated electronic record shared across formal care providers (with patient consent).

- **Research**

Very little palliative care research has been carried out in Lakes. Some projects associated with staff undertaking tertiary study have been completed but the results are not widely available.

- **Education**

**Generalist level**

Locally, it is the responsibility of specialist palliative care services to provide education and support to generalists such as general practice, residential care facilities, support workers, family, carers as well as hospital staff.

Palliative care education for generalists in Lakes is provided by the hospices. Each hospice delivers the range and number of programmes in response to perceived local need and within their available resources although there are some wider Midland regional approaches e.g. Taupo Hospice facilitates a videoconference link to the Waikato palliative care ground round (clinical education session).

Regionally, a Midland Palliative Care education work group has been established to facilitate sharing of resources and to promote consistency of approach throughout Midland. The Midland Palliative Care Nurses and Carers Education Strategy<sup>25</sup> provides a view of the programmes available to build palliative care understanding and knowledge within the nursing and carer workforce. A Midland Education calendar is made available via the hospices and the Midland Cancer Network website.

Additional Ministry of Health funding to implement new services defined in the National Palliative Care Service Specifications (Draft 2008) and 'Boost Hospice' funding targeted (amongst other things) the improvement of education for generalists and implementation of end of life care which includes an education component. Both hospices increased their staffing to meet the requirement for increased education and for implementing LCP.

Nationally, Hospice New Zealand is actively involved in education and workforce development and has developed a range of education packages that are used by member hospices. This provides a cost effective approach to the development and delivery of consistent palliative care education programmes and resources throughout New Zealand. These packages are used by the hospice in Lakes DHB. In 2011 Hospice New Zealand, with the support of the Ministry of Health, developed an education package 'Fundamentals of Palliative Care'. This provides a nationally consistent programme for nursing and allied health staff and care assistants. This programme is an important component of the Midland framework has been included in the range of programmes offered locally by hospices. The initial focus is to use this programme to support the development of palliative care knowledge and skill in the residential care sector.

Different approaches are taken by the two hospices to resourcing education. Taupo has a dedicated part time resource for education and LCP. Rotorua Hospice takes a more generic approach to nursing roles with shared participation in delivering patient coordination and care, education, grief and bereavement support etc. While this creates a more multi skilled workforce and provides greater flexibility when covering for leave etc it does have disadvantages i.e. people usually have competing demands and without dedicated time education is often not prioritised. However, the hospice has continued to make changes and improvements to how and where they deliver education which has resulted in an increase in the number of programmes and sessions offered.

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<sup>25</sup> Midland Specialist Palliative Care Framework for Generalist Nursing and Carer Education, Midland Cancer Network, September 2009

Details of the range of education programmes and sessions offered in Lakes are listed in the individual hospice service outlines – Appendices 5 and 6.

Particular gaps identified in education for generalists in Lakes.

- Education of acute hospital staff on contemporary palliative care. Requires agreement with hospital professional development teams for the hospices to:
  - have a regular slot on orientation programmes
  - present palliative care topics at nursing study days
  - have undergraduate nurse placements with hospice services.
- Palliative care education for allied health. Palliative care is not covered at undergraduate level or in any allied health training and so some are underprepared in dealing with palliative people. Some allied health staff find it difficult to develop skills in palliative care as an area of specialisation or special interest.
- Medical education for hospital medical staff and GPs. This requires ongoing emphasis to continue to build the capability of generalists and to encourage timely referral to specialist services for more complex cases. Is limited by the availability of specialist palliative medicine resource to provide this throughout Lakes. Further development of this education needs to continue in conjunction with the Waikato Palliative Care Service and supported by the Lakes hospitals and PHO professional development teams.

The draft Resource and Capability Framework identifies several enablers of care across all services to facilitate the integration of care. Education and training for generalist providers, including practice based education to support a palliative approach, is identified as an enabler.

The recommendations include:

1. the development of qualification appropriate for the allied health workforce to maximise the potential for discipline specific skill they bring to the provision of palliative care services; and
2. work with university and other education providers to develop e-learning opportunities which will enable staff who live outside of main centres to access training and qualifications.

### **Specialist level**

Education and development of specialist nurses and others in hospices is generally achieved through a combination of in-service activities, access to learning resources and agreed individual development plans. There are a number of postgraduate training programmes available through a range of providers in New Zealand. There is some access to Health Workforce New Zealand funding to support staff post graduate training/education in palliative care (mostly targeting nursing and medical staff) and BNI Palliative Care Scholarships through Hospice New Zealand (for hospice staff or Hospice NZ individual members).

A significant gap relates to knowledge and skill development of the existing palliative care workforce in caring for an increasing range of nonmalignant diseases and those with dementia

- **Regional and national involvement**

Representatives of Rotorua Community Hospice and Lake Taupo Hospice actively participate in the Midland Palliative Care Workgroup and have developed relationships with hospices within Midland and in other parts of New Zealand. They are members of Hospice New Zealand and involved in national activities.

- **Palliative care health promotion**

While there is no specific strategy around raising public awareness of palliative care services in Lakes, the hospice services are promoted in a variety of ways, including:

- national campaigns under the umbrella of Hospice New Zealand

- hospice newsletters, websites, information brochures
- local hospice promotion, events and fundraising
- speaking engagements
- word of mouth 'marketing'.

It is noted the Lakes DHB website does not contain any information to explain palliative care, the specialist services available for Lakes residents and how to access these.

## 5.6. Funding

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### Generalist palliative care services

- Primary Health Organisations (PHOs)  
PHOs are funded at a population level, based on the characteristics of a practice's enrolled population. Community palliative care services delivered through PHOs for their enrolled populations do not have defined funding streams or specified services. They are considered to be a component of essential primary health care services.

However, the Ministry of Health has provided funding (via DHBs to PHOs) to develop specific programmes to improve the provision of primary care. An example is the Services to Improve Access (SIA) programme under which the two PHOs in Lakes have developed specific initiatives for general practices to improve care of terminally ill people. Each PHO offers different levels of funding and for different purposes – details are outlined in Appendix 7.

- Hospital based palliative care  
Palliative care is considered a part of usual treatment and care across a range of specialties within the hospital environment. There is no identifiable funding within the hospital service specifically for palliative care.
- District nursing and allied health services  
These services are funded as a part of the DHB community services.

Visiting palliative people is currently part of the Taupo district nurses overall case load. The district nursing service is funded based on an estimate of 110 palliative people per year. Equipment and consumables used by the district nurses are included such as pumps and medication. There is no information that was able to be provided for this report on how many palliative people district nurses actually saw relative to the 110 people funded or the portion of time district nurses would spend with palliative people relative to other people. The reporting for this service is not to a level that correctly reports palliative care activity at a patient level. This is currently being addressed by the Lakes DHB business support team.

The portion of funding or volumes of work for other DHB allied health services has not been identified.

- Home based support  
Home help and personal care is funded differently between Rotorua and Taupo
  - Rotorua hospice is funded by the DHB to deliver personal care for palliative people according to need. Home help is accessed via the Lakes NASC services if the person meets the eligibility criteria.
  - In Taupo for both home help and personal care, access and provision of a range of DHB contracted home and community support services is through Lakes NASC service.
  - Hospice volunteers and hospice employed night nursing team are used to support people with respite in the home.
- Short term residential care  
Respite care and end of life care in a residential facility is funded differently between Rotorua and Taupo.
  - Rotorua - The hospice receives funding for this within their DHB bulk funding. The Hospice funds up to ten days of respite within a total of 30 days of respite/residential end of life allocation for each person and pays the care facility direct.
  - Taupo - Taupo Hospice has no specific funding for respite or end of life care. Lakes NASC holds a limited short term residential palliative budget that allows Taupo Hospice to allocate services based on assessed need and the provider invoices Lakes NASC directly. This is mostly used for end of life care.

All age related residential care providers have DHB contract agreements to provide short term residential respite services - thus giving people a choice of providers.

Where a person may require support for longer than 30 days, the assessment and care plan of hospice team continues, and the funding of the service generally transfers to DHB long term support funded service. There may be exceptions if the person is young and the need for care is for more than six months where access to funding will be through MOH DSS or Long term Support - Chronic Health Conditions.

- Other NGOs including Māori health provider services receive funding from the DHB to provide a range of care and support services inclusive of palliative and end of life care. Examples include:
  - Aroha Mai Cancer Support Group – a Māori based group who support people who have cancer through treatment, end of life and support for whānau after death.
  - Rongoā services – traditional Māori healing services which includes people with palliative conditions.

Details of their funding have not been included because this is not easily apportioned to palliative care support.

### **Specialist palliative care**

Hospices receive funding in two ways.

- Ministry of Health funding via District Health Board contract agreements as outlined in Operational Framework and annual plans
- Community fundraising activities, bequests and donations from individuals and organisations.

Identifiable funding provided via Lakes DHB for specialist palliative care services is detailed in Appendix 8. This does not include the proportion of Hospice community funding through fundraising, bequests, donations etc (which represents about 30% of the hospices costs).

National Palliative Care Service Specifications (NPCSS) were developed in 2001 by the Ministry of Health as part of the Nationwide Service Framework. Purchase unit codes (PUCs) are allocated to each aspect of the service and DHBs use them to specify volumes and funding in their contracts for regional/local clinical services. Most of these PUCs are still broadly used today by DHBs but PUC values and processes to determine volumes and changes to price are not consistent between DHBs. Additional PUCs have occurred with revised service specifications and new services.

In 2006, a review of the NPCSS was initiated and resulted in the first draft of new service specifications being released on February 2008. These service specifications currently remain in draft and included new services with assigned funding but no national price for specific services, thus requiring DHBs to consider alternative ways of funding hospices.

Since 2008, Lakes DHB has purchased services from Rotorua and Taupo hospices on a block funding arrangement and using existing PUC categories within two service specifications. There are no specific contract volumes agreed. This allows hospices to decide how services are developed to meet community needs but the DHB expects there will be no service gaps.

In addition to the block funding arrangement, from time to time additional MOH funding has been allocated to the hospices for specific initiatives. In recent years these were:

- 2008/09 - Funding for the implementation of end of life care, education to generalists, 24/7 telephone advice. These were services defined in the National Palliative Care Service Specifications (draft, MOH 2008).
- 2009 - \$60M boost hospice funding nationally over four financial years (2009/10 to 2012/13) to expand care and services and to help hospices meet their current financial challenges. The amount each hospice receives was determined by national hospice and DHB surveys, and is expected to ensure 70% of hospice costs are covered by MOH/DHB funding. Boost Hospice Funding is confirmed for 4 years from 1 July 2009.
- \$1.3 million of the total 'Boost Hospice' funding was allocated to some selected hospices to help address difficulties in accessing palliative care services. This 'Access to Care Pressures' funding was to be used to address key gaps in the hospice services as identified in the qualitative results of



the national stocktake of specialist palliative care services<sup>26</sup>. This allocation was provided for the 2009/2010 and 2010/2011 years and has been confirmed for the 2011/12 and 2012/13 years.

Both Hospices within Lakes DHB received 'Access to Care Pressures' funding for the following purposes:

- For resources to develop a hub and spoke model with a specialist service for additional medical specialist expertise
- To develop and recruit additional nursing and grief and loss workforce.

The additional 'Boost' and 'Access to Care Pressure' funding for Taupo has resulted in:

- increased nursing resource which has improved the number of follow up assessments that can be provided
- the implementation of LCP
- an improved range and availability of education sessions
- introduction of a visiting medical specialist service
- an extended range of bereavement services.

The additional 'Boost' and 'Access to Care Pressure' funding for Rotorua has resulted in:

- increased nursing resource which also contributed time to increase grief and loss support
- the implementation of LCP
- additional education sessions for residential care
- introduction of a visiting medical specialist service.

'Boost Hospice' funding is paid to the hospices in 12 even monthly payments. This does not attract any volume or price increases because it is passed on directly from the amount received from MOH. It is not yet known whether the Boost Hospice Funding will continue. Currently the additional funding is expected to cease on 30 June 2013. This poses specific challenges for hospices as this funding supports their current level of services.

In 2009, after the 'Boost Funding' allocation, public funding was expected to cover 70% of hospice costs. The shortfall of at least 30% is raised by hospices through hospice shops, community fundraising activities and from sponsorship, bequests and donations from individuals and organisations.

Donations of services 'in kind' and unpaid volunteers make a significant contribution the running of non clinical hospice services. Hospices would not provide their current range and level of services without these contributions.

### **Inter district flows**

There are people who live on or close to the boundaries between different DHBs, and it may be more appropriate for them to receive service/s from an alternate DHB area. An example is the boundary between Bay of Plenty and Lakes DHB around the Murupara/Ruatahuna district. In this example Hospice EBOP provides services but the residents may prefer to access residential care in Rotorua. The cost of these services is covered by DHB interdistrict flow funding (IDF) between Lakes and BOP DHBs for up to six people a year. Equipment is usually supplied by arrangement between the hospices and/or hospital service. Inter district flow agreements with other DHBs are limited and individual consideration is required on a case by case basis.

A map which defines where the boundaries are between DHBs is available and can be used to clarify the operational issues around who provides services, especially in remote rural locations where providing nurse visits is resource intensive and more expensive.

### **Contract agreement and performance monitoring**

The allocation of funding and monitoring of performance against contract for specialist palliative care service providers in Lakes DHB is the responsibility of the Planning and Funding Portfolio Manager for Health of Older People and Disabilities.

The hospices submit quarterly returns of people and activity data in a format prescribed by the Ministry of Health (MoH monitoring returns) and any other reports required by Planning and Funding. The

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<sup>26</sup> Gap Analysis of Specialist Palliative Care in New Zealand – Providing a national overview of hospice and hospital-based services, Ministry of Health, December 2009.

Portfolio Manager meets regularly with the hospice managers to review performance against contract and identify issues.

For generalist nursing services in the community who undertake palliative care services:

- Health Reporoa Nursing services is covered by P&F Portfolio Manager for Primary Health
- District Nursing, Aged Related Residential Care, Home & Community Nursing is covered by P&F Portfolio Manager for Health of Older People and Disabilities

### **Identified funding issues**

Current issues related to funding palliative care services identified during the stakeholder meetings include:

- the funding pool for specialist palliative care in residential care services is very limited and when a person requires support for more than a few weeks this can leave people in very vulnerable situation
- demand is estimated to grow but the pool of public funding is not
- hospices in Lakes DHB are not currently funded on actual volume which means any change in demand will need to be managed closely and new ways of supporting an appropriate level of services need to be explored
- with the current economic climate in New Zealand hospices will find it increasingly difficult to maintain the current level of financial support from the community. Already hospices have noticed it more difficult to obtain community grants with more organisations competing for a smaller pool of money, and the level of financial support from individuals and organisations, in general, is more difficult to sustain
- gaps in reporting makes it difficult to understand or monitor care provided to assess value for money.

At the time of completing the gap analysis information required by the Ministry of Health in 2009, Lakes identified that there are funding issues with different criteria for different residential care/end of life funding streams e.g. if a person does not fit access criteria to funding streams such as health of older people, interim funding pool, close in age and interest and requires residential care support up to six months (which is the timeframe that defines a long term disability) the DHB pays 100% of the cost of residential care for various timeframes. Whereas a similarly old frail person may be admitted into age residential care and be expected to part fund their care (e.g. use their superannuation) and still die within 6 months.

Currently the way that specialist palliative care services are funded is different in each DHB within Midland and this is also the case throughout New Zealand. The funding is fragmented and in general, there is a high degree of funding services based on predicted costs from previous year's activities. This approach supports the funding of services based on historical activities rather than assessed need and can perpetuate inequities. Data is often focussed on deaths rather than services provided.

DHB Planning and Funding managers have identified the lack of national service specifications for palliative care as an issue. The need for a new national funding model for specialist palliative care has been highlighted in a number of the current national initiatives. Work on the new national specialist palliative care service specifications and associated documents have not proceeded as quickly as originally planned. These were intended to provide a greater level of clarity to the planning, provision and purchasing of palliative care services. Included in the Ministry of Health current national work plan for palliative care is work on a discussion document on the national funding model. It is expected that a new national funding model will be developed following completion of the Resource and Capability Framework and Service Specifications.

Included in the recommendations contained in the draft Resource and Capability Framework is the need to change the current funding models to incentivise effective palliative care outcomes (at both a patient and systems level) instead of on the basis of historical services delivery.

## 6. The future

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### 6.1. Increasing need for palliative care

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The population's need for palliative care is being driven by a range of factors which increase the need for care delivered by both specialists and generalists including:

- population growth and a growth in the number of deaths
- ageing population – a greater proportion of people in the older age group means more people will require palliative care
- people living longer – likely to see a rise in chronic diseases such as heart disease, cerebral vascular disease, respiratory disease and cancer
- increasing complexity of care – more people with co-morbid conditions including more with dementia
- increase in rates of cancer and deaths from cancer – cancer has had the biggest influence on need for palliative care because most cancer deaths involve a period when palliative care is required
- Based on the New Zealand Cancer Registry and the Ministry of Health's Mortality Collection data, cancer is the leading cause of death in New Zealand accounting for 29% of all deaths. While age-standardised cancer incidence rates are falling, the growth in the older population will increase overall cancer registrations substantially
- increase in referral of people with nonmalignant diseases due to an increased awareness that people with nonmalignant diseases can benefit from palliative care services
- increase in referrals overall as result of improved awareness of the services available and the benefits
- increase in utilisation by Māori, Pacific People and other ethnic groups as a result of services being more responsive to cultural needs leading to greater acceptance by these groups.

In addition, the hospices report additional demands being placed on their services because of the changing family structures. They observe more people living alone with little or no family support as families are smaller, more dispersed or are elderly themselves. This increases demand for support services such as home help and personal care and can make it more difficult for people to stay at home and to die at home.

Changes in clinical practice and policy in other clinical specialties (e.g. aged care and oncology) will also influence patterns of referral and demand for services. New models of care are being developed for other specialties and palliative care is increasingly being included as a key component in patient pathways. There is a need to ensure both the availability of palliative care and good integration of palliative care with other services to support these new models.

An example is the Medical Oncology Cranleigh Report (2011)<sup>27</sup> which concludes that “overall, the increase in numbers of people with cancer, survivorship, and treatment duration, the changing care complexity and funding pressures are likely to significantly impact workloads and service sustainability.” The Ministry of Health recognises that in implementing new models of care for medical oncology there will be impact on other services provided by district health boards and non-government organisations. The report outlines that service and capacity pressures in other cancer related services, particularly palliative care, are affecting medical oncology capacity. It states “the sector consensus is that 10-20% of patients occupying medical oncology inpatient beds may not need specific medical oncology input and could be better managed in a specialist palliative care facility.”

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<sup>27</sup> Report to the Ministry of Health - New Models of Care for Medical Oncology, Cranleigh Health, 5 October 2011.

The New Zealand Lung Cancer Standards<sup>28</sup> released in August 2011 include the availability of palliative care as a specific standard, i.e. Standard 12: *Patients who cannot be offered curative treatment, as well as those with a significant symptom burden, should be offered early access to palliative care services.*

In Lakes DHB, respiratory physicians see people discharged from oncology to assess if there are any immediate or specific needs requiring intervention. Some of the people are towards the end of life and require significant clinical input in terms of advance care planning. The Lakes DHB stocktake against the Lung Cancer Standards noted “the need for higher level palliative care services (access to palliative care nurses and medical specialist)”.

The key to caring well for people who will die in the (relatively) near future is to understand how they may die, and then plan appropriately. Since diseases affect individuals in different ways, prognosis is often difficult to estimate. None the less, it seems that people with specific diseases and their carers often have common patterns of experiences, symptoms, and needs as the illness progresses<sup>29</sup>. Three typical trajectories have been developed so far and are increasingly used to conceptualise palliative care needs – refer to Appendix 9.

Physical, social, psychological and spiritual needs of the palliative person and their carers are likely to vary according to the trajectory they are following. Specialist palliative care services that traditionally have cared for those with cancer are being challenged to meet the varied needs of those with other chronic conditions and especially those with dementia.

## 6.2. Cancer and chronic disease

Overall in New Zealand, cancer is now the leading cause of death in New Zealand accounting for 29% of deaths from all causes. Seventy-two percent of all deaths from cancer in 2008 occurred in people aged 65 and over.

According to the Ministry of Health, for the period 2006-2008 Lakes DHB had the second highest age-standardised cancer registration rate of all DHBs (360.8 per 100,000) and was significantly higher than the national rate (344 per 100,000). Lakes DHB standardised death rate from cancer is the second highest across all DHBs (156.7 per 100,000) which is significantly higher than the national average (132.3 per 100,000). It is especially marked for lung cancer which reflects the high rate of smoking (2<sup>nd</sup> in the country) and the high proportion of Māori (34% in 2008) who return smoking rates more than double that of non- Māori.

The highest age-standardised rates of death in the total New Zealand population in 2008 were from:

- cancer
- ischaemic heart disease
- cerebrovascular disease.

The highest age-standardised rates of death in the Māori population in 2008 were from:

- cancer
- ischaemic heart disease
- chronic lower respiratory diseases.

Lung cancer was the leading cause of cancer death by age-standardised rate for both Māori and non-Māori in 2008.

Of the 754 recorded deaths in Lakes in 2008:

- 31% were from cancers (ICD C00-C96). Some 231 deaths were attributed to all malignant neoplasms of which the most common were those of the digestive organs (76) and respiratory and intrathoracic organs (48).

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<sup>28</sup> National Lung Cancer Working Group. 2011. Standards of Service Provision for Lung Cancer Patients in New Zealand. Wellington: Ministry of Health.  
[http://www.MoH.govt.nz/MoH.nsf/Files/cancer/\\$file/lung-cancer-service-standards-aug11.pdf](http://www.MoH.govt.nz/MoH.nsf/Files/cancer/$file/lung-cancer-service-standards-aug11.pdf)

<sup>29</sup> Murray SA, Kendall M, Boyd K, Sheikh A. *Illness trajectories and palliative care*. BMJ April 2005; vol 330, pp 1007-1011.

- 18% were from ischaemic heart disease. There were some 137 deaths in the ICD Classes I20-25. The age standardised rates show the rate within Lakes is not significantly different from the national rate. However, across the country, the rate for Māori males is some 85.4% higher than that for non-Māori males.
- 8% (59) were from chronic lower respiratory diseases (J40-J47)
- 7% (52) were from cerebrovascular disease (I60-I690)
- 4.5% (34) were from accidents (X00-X59)
- 4% (30) were from diabetes mellitus (E10-E14)

Recent data in Table 7 demonstrates a changing proportion of people with a non-cancer diagnosis in Rotorua Hospice. This could be attributed to an increasing prevalence of non-cancer conditions, awareness of the role and value of palliative care and hospice services for those with nonmalignant diseases and an increased public awareness that hospice services are not just for those with cancer.

Taupo has experienced a less consistent change in the primary diagnosis of people. However the patient numbers are small and changes impact more noticeably on the percentage. In addition, 2007 data is inconsistent as a large proportion were categorised as 'other' by comparison to recent years. Changes are more easily seen in the actual patient numbers in Figure 4 below.

**Table 7: Diagnosis hospice patient deaths & discharges 2007-2010**

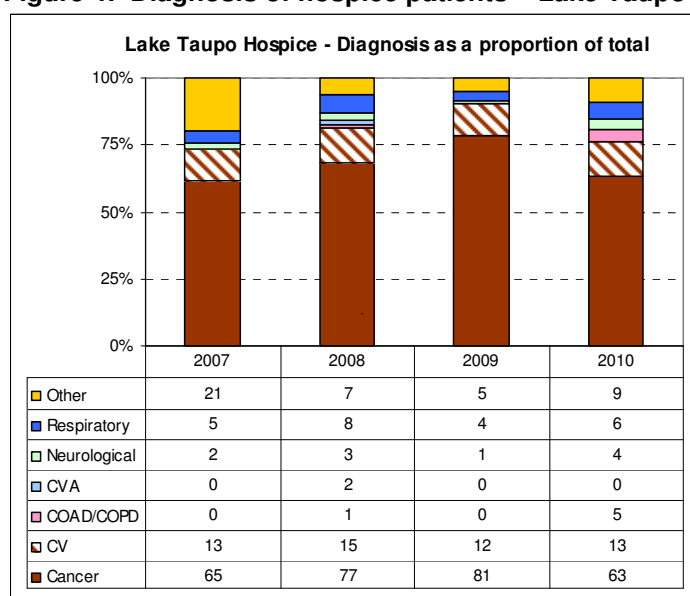
|                   |                    | 2007 | 2008 | 2009 | 2010 |
|-------------------|--------------------|------|------|------|------|
| <b>Cancer</b>     | Lake Taupo Hospice | 61%  | 68%  | 79%  | 63%  |
|                   | Rotorua Hospice    | 78%  | 78%  | 75%  | 69%  |
| <b>Non Cancer</b> | Lake Taupo Hospice | 39%  | 32%  | 21%  | 37%  |
|                   | Rotorua Hospice    | 22%  | 21%  | 25%  | 32%  |

Source: Hospice MoH monitoring returns

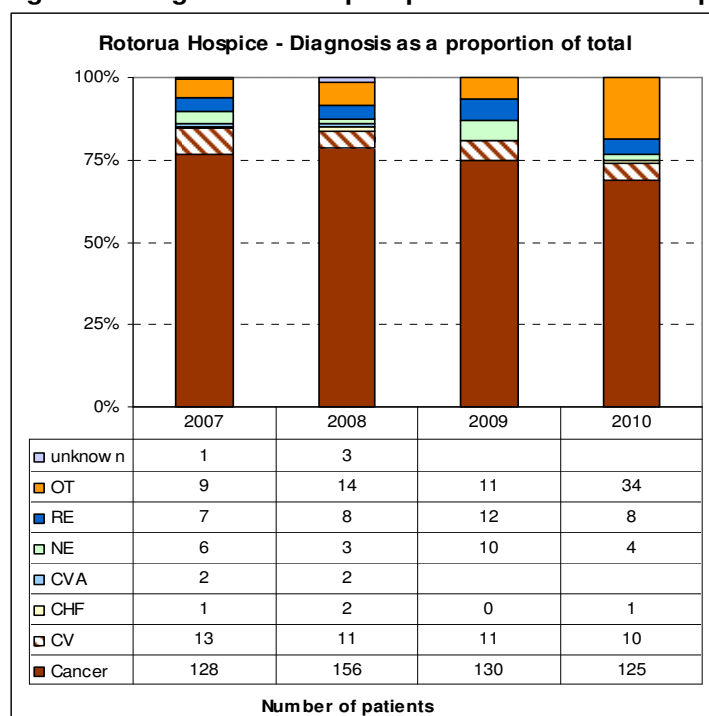
Note this data is based on the primary diagnosis of the patient which may or may not be the exact cause of death i.e. a patient with cancer as a primary diagnosis may have died of another cause.

Figures 4 and 5 shows a breakdown of the number of people by diagnosis and shows the overall makeup of diagnosis groups for people who died or were transferred within each calendar year.

**Figure 4: Diagnosis of hospice patients – Lake Taupo Hospice**



**Figure 5: Diagnosis of hospice patients – Rotorua Hospice**



### 6.3. Deaths in Lakes

In 2004, Lakes DHB had significantly higher avoidable mortality than New Zealand overall – see Table 8.

**Table 8: Avoidable mortality numbers and rates, 2004**

| Avoidable mortality | Count | Age-standardised rate per 100,000 |
|---------------------|-------|-----------------------------------|
| Lakes               | 254   | 212.6                             |
| New Zealand         | 8,316 | 169.1                             |

*Source: An Assessment of Health Needs in Lakes DHB summary report, 2008*

#### Place of death

In UK, despite most people (56-74%) expressing a preference to die at home, only 35% actually achieve this aim (National Audit Office NAO, 2008)<sup>30</sup>. The majority of deaths in England occur in an acute hospital setting following prolonged, chronic illness. In Australia only 16% of people die at home. Twenty percent of people die in hospices and 10% in nursing homes. The rest (around 54%) die in hospitals.<sup>31</sup>

The *National Health Needs Analysis for Palliative Care*<sup>32</sup> indicates that on a national basis most deaths in New Zealand occurred in a hospital setting (34%) followed by residential care (31%) and private residence (22%). A small number of deaths were in a hospice inpatient unit.

<sup>30</sup> End of Life care, 2010, Vol 4 No 3

<sup>31</sup> CareSearch Preferred Place of Death [www.caesearch.com.au](http://www.caesearch.com.au) Accessed 24 August 2011.

<sup>32</sup> National Health Needs Analysis for Palliative Care, Cancer Control Council, June 2011.

A full copy of the National HNA for Palliative Care is available from the publications section on the Cancer Control New Zealand website <http://www.cancercontrolnz.govt.nz/about-us/publications>

In Lakes, the proportion of those who die in hospital is less than Australia, UK and New Zealand as a whole. During the 4 year period 2007 to 2010, an average of 25% of all deaths in the Lakes region occurred in either Taupo or Rotorua Hospital. See Table 9.

**Table 9: Ratio of deaths in hospital – Lakes 2007-2010**

|      | Taupo<br>Hospital<br>deaths | Rotorua<br>Hospital<br>deaths | Total<br>deaths in<br>Hospital | All deaths in<br>Lakes | Deaths in hospital<br>as a % of all<br>deaths |
|------|-----------------------------|-------------------------------|--------------------------------|------------------------|---|
| 2007 | 35                          | 144                           | 179                            | 800                    | 22%   |
| 2008 | 46                          | 139                           | 185                            | 730                    | 25%   |
| 2009 | 45                          | 158                           | 203                            | 780                    | 26%   |
| 2010 | 43                          | 145                           | 188                            | 710                    | 26%   |

Source: Lakes DHB and Statistics New Zealand

It is not known how many of the total deaths in the region occur at home or residential care facilities etc, nor do we have information of where people would prefer to die. However, we do have information on where people who are patients of the hospice services die, see Table 10 below.

**Table 10: Place of death of hospice patients - 2010**

|                        | Taupo<br>Number ( ) | Rotorua<br>Number ( ) |
|------------------------|---------------------|-----------------------|
| Home                   | 55% (48)            | 71% (124)             |
| Hospital               | 20% (18)            | 11% (19)              |
| Residential care home* | 24% (21)            | 18% (32)              |
| Other                  | 1% (1)              |                       |

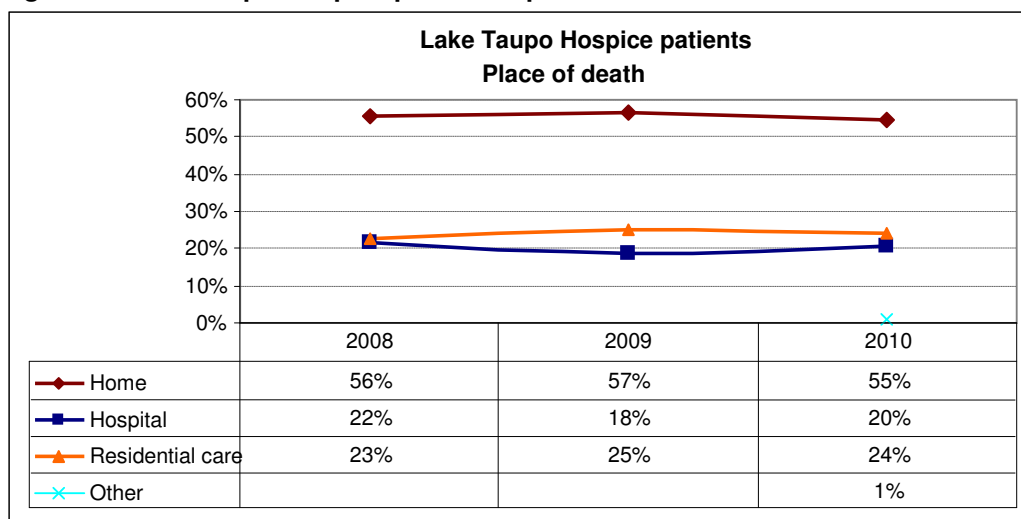
\*Includes those where the ARC is their 'home'

Source: Hospice MOH monitoring returns

Lakes DHB palliative care service model is community based. A key objective is to support people to die at their place of choosing, which for most is at home. Both Taupo and Rotorua areas show a high proportion of hospice patient deaths occurring at home – Rotorua has a particularly high proportion of home deaths at 71%. We have not researched in detail the reasons for the differences in Taupo and Rotorua. However, it is more difficult to provide end of life care in the home for those that live in rurally isolated areas (Southern Taupo/Turangi region in particular) so those people who experience more complex problems or have little family support are more likely to be placed in residential care or hospitalised than those who have better access to GP and community nursing support. Another contributing factor may be the difference in service delivery where Rotorua provides a complete nursing service and access to equipment and support. Whereas in Taupo this service is split between hospice and district nursing and access to hospital services may be more readily sought.

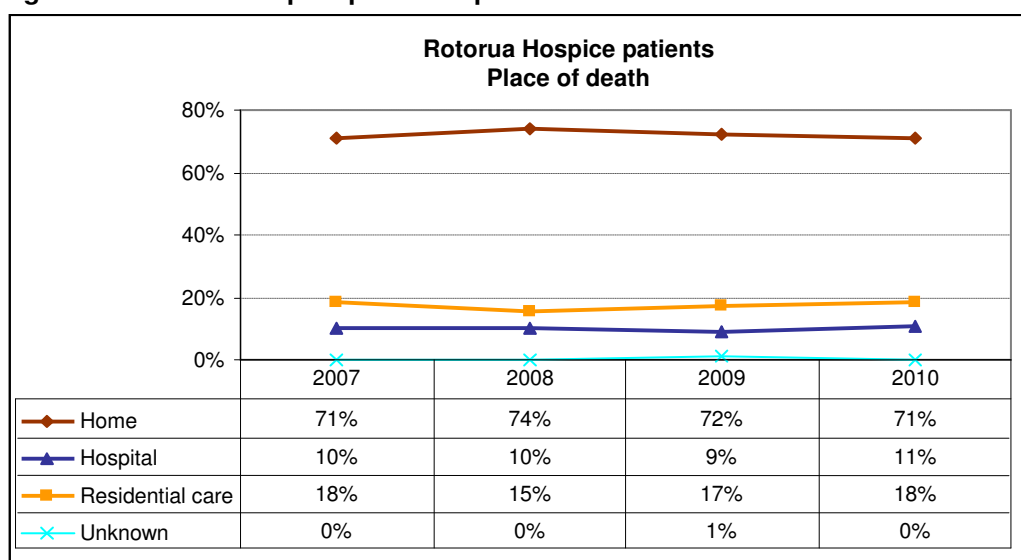
Between 2008 and 2010, very little change is seen in the place of death of the hospice patients - see Figures 6 and 7.

**Figure 6: Lake Taupo Hospice patients – place of death**



Source: Hospice Ministry of Health monitoring returns

**Figure 7: Rotorua Hospice patients - place of death**



Source: Hospice Ministry of Health monitoring returns

### Projected number of deaths

According to projections by Statistics New Zealand the number of deaths in Lakes is estimated to reach 820 by the year 2016 – see Figure 8.

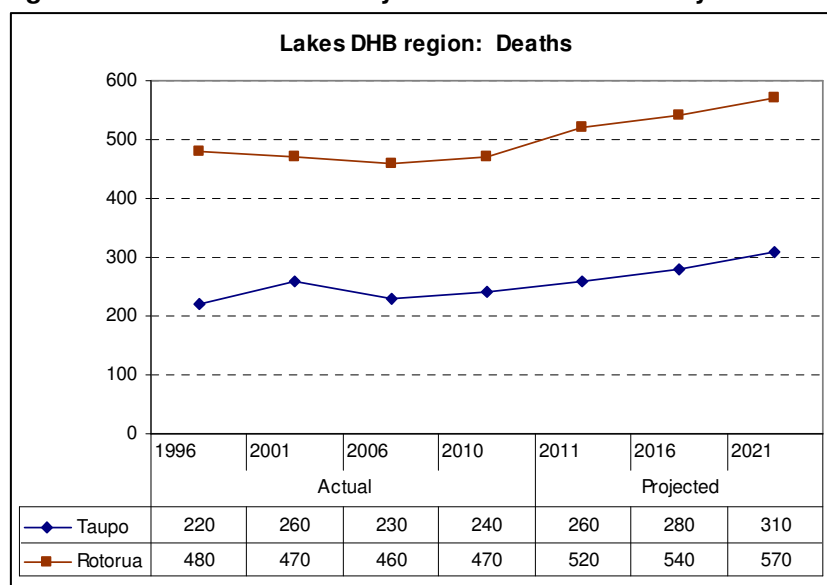
- Rotorua is estimated to have a 3.8% increase in the number of annual deaths in 2016 compared to 2011 (520 in 2011 to 540 in 2016)
- Taupo is estimated to have a 7.7% increase in the number of annual deaths in 2016 compared to 2011 (260 in 2011 to 280 in 2016).

The impact of the increase in deaths will be greater for Taupo than Rotorua. However, the numbers are small and therefore it is relatively difficult to quantify in terms of impact on resources and revenue/costs for:

- Hospice
- GPs
- Residential care
- Taupo Hospital / Rotorua Hospital



**Figure 8: Number of deaths by territorial local authority – actual and projected**



Source: Statistics New Zealand

In 2010, 37% of the deaths in Taupo TLA were patients of Taupo Hospice (n = 88 of 240) and 37% in Rotorua were patients of Rotorua Hospice (n = 175 of 470). The cause of death for the remaining two thirds of deaths would include:

- sudden/unexpected death e.g. heart attack, major trauma
- natural death e.g. old age or other illnesses where specialist palliative care was not required
- child and infant deaths.

And it is likely there would be a percentage that died without specialist palliative care input who may have benefited from it. The reasons could include:

- non referral – lack of recognition that the person was dying
- lack of awareness of palliative care/hospice services
- declined referral to hospice or palliative care by patient/family/whānau.

However, there are no sources of information on which to base an estimate of what this percentage might be.

### **Projected number of hospice patient deaths**

- **Taupo**

Statistics NZ is estimating the number of deaths to rise to 260 by 2011 and to 280 for each of the years 2012 to 2016<sup>33</sup>. A comparison of actual vs projected for the last 3 years suggests that Statistics NZ projections are generous.

Assuming no change in the proportion of deaths in the area that have hospice care and using Statistics NZ projections, we estimate the number of deaths of Taupo Hospice people could be:

- 2011 – 97 deaths (an increase of 1% from 2010 actual)
- 2016 – 104 deaths (an increase of 7% from 2011 estimated)

<sup>33</sup> Note: There is no change in Statistics NZ estimations of deaths between the 5 year census periods. For reference see [http://www.stats.govt.nz/browse\\_for\\_stats/people\\_and\\_communities/geographic-areas/local-population-trends.aspx](http://www.stats.govt.nz/browse_for_stats/people_and_communities/geographic-areas/local-population-trends.aspx)

**Table 11: Projected number of Taupo Hospice deaths:**

| Calendar year                    | Actual deaths |            |            | Estimated deaths |      |
|----------------------------------|---------------|------------|------------|------------------|------|
|                                  | 2008          | 2009       | 2010       | 2011             | 2016 |
| Hospice pt deaths in Taupo Hosp  | 17            | 14         | 13         | 15               | 16   |
| Taupo Hospital deaths*           | 46            | 43         | 40         | 45               | 48   |
|                                  | <b>37%</b>    | <b>33%</b> | <b>33%</b> | 33%              | 33%  |
| All Taupo Hospice patient deaths | 88            | 92         | 88         | 97               | 104  |
| All deaths in Taupo district     | 250           | 250        | 240        | 260              | 280  |
|                                  | <b>35%</b>    | <b>37%</b> | <b>37%</b> | 37%              | 37%  |

\* excludes deaths in ED

Source: Lake Taupo Hospice MOH monitoring returns and Lakes DHB patient management system

- Rotorua

Statistics NZ is estimating the number of deaths in Rotorua TA to rise to 520 by 2011, and to 540 in each of the years 2012 to 2016<sup>32</sup>. A comparison of actual vs projected for the last 3 years suggests that Statistics NZ projections are generous.

Assuming no change in the proportion of deaths in the area that have hospice care and using Statistics NZ projections, we estimate the number of deaths of Rotorua Hospice people could be:

- 2011 – 192 deaths (an increase of 10% from 2010 actual)
- 2016 – 200 deaths (an increase of 4% from 2011 estimated)

**Table 12: Projected number of Rotorua Hospice deaths:**

| Calendar year                      | Actual deaths |      |      |      | Estimated deaths |      |
|------------------------------------|---------------|------|------|------|------------------|------|
|                                    | 2007          | 2008 | 2009 | 2010 | 2011             | 2016 |
| Hospice pt deaths in Rotorua Hosp  | 17            | 19   | 13   | 18   | 20               | 21   |
| Rotorua Hospital deaths*           | 138           | 136  | 150  | 139  | 156              | 162  |
|                                    | 12%           | 14%  | 9%   | 13%  | 13%              | 13%  |
| All Rotorua Hospice patient deaths | 164           | 183  | 163  | 175  | 192              | 200  |
| All deaths in Rotorua district     | 540           | 480  | 530  | 470  | 520              | 540  |
|                                    | 30%           | 38%  | 31%  | 37%  | 37%              | 37%  |

\* excludes obstetrics, neonatal, paediatrics & ED

Source: Rotorua Hospice MOH monitoring returns and Lakes DHB patient management system

#### 6.4. National Palliative Care Health Needs Assessment (HNA) - estimate of need.

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The *National Health Needs Analysis for Palliative Care* published in 2011 provides estimates of the number of people who would benefit from palliative care. Mortality Collection and Hospital Admission data for 2005, 2006 and 2007 was analysed to establish how many people might have benefited from palliative care and future estimates made based on population growth.

The mid-range estimate for adults in Lakes DHB (those aged 20 yrs+) indicates 52.6% of all deaths would benefit from palliative care. This was projected into an estimate of the likely number based on population growth.

**Table 13: Mid range estimate of the number of adults who would benefit from palliative care**

| LAKES           | Mid-range estimate number likely to benefit from palliative care p.a. | Increase between periods (number of people and % increase) |
|-----------------|---|--|
| Baseline (2006) | 367   |  |
| Projected 2016  | 396   | 29 (8%)  |
| Projected 2026  | 409   | 42 (3%)  |

*Source: National Health Needs Assessment for Palliative Care Phase 1 report, Palliative Care Council of New Zealand, June 2011 p. 34*

The HNA states there is limited evidence available on how the number of people who could benefit from palliative care can be allocated into the following groups:

- Those requiring specialist palliative care
- Those who could be cared for adequately by generalist palliative care providers.

Because of the difficulty identifying the likely split of people between the two service levels the estimation is of limited use in relating to current services in Lakes and planning future service volumes.

In 2010, Lakes specialist palliative care services (the hospices) provided care for a total of 263 people who died. This indicates that Lakes DHB specialist palliative care services are currently seeing more than 66% of the number estimated in the HNA to have palliative care needs by 2016. There will always be a proportion that will be adequately cared for by generalists and it could be assumed that there will be some that may have benefited from specialist palliative care but were not referred, declined referral or did not know about palliative care services.

The HNA states that although research is limited to date, there is some evidence showing that palliative care for people in more deprived areas requires more resources than in most affluent areas. A study undertaken by St Christopher's Hospice in London found that people in the most deprived districts of their catchment required, on average, twice as many home visits as people from more affluent districts. After the annual incidence of deaths, deprivation is therefore considered the second most important factor affecting palliative care resource needs in a population.

## 6.5. Capacity to meet future demand.

The specialist services currently report an increasing trend of referrals – see tables 14 and 15.

**Table 14: Lake Taupo Hospice referrals**

| Financial year                | Actual referrals                                     | Increase from previous year |
|-------------------------------|--|-----------------------------|
| 2009/10                       | 146  |                             |
| 2010/11                       | 165  | +19 (13%)                   |
| 2011/12<br>(to 16 March 2012) | 124 (37/52 weeks)<br><i>Estimate full year * 174</i> | <i>Est +9 (5%)</i>          |

\*estimate is based on average of current actual multiplied by 52 weeks

**Table 15: Rotorua Hospice referrals**

| Financial year                | Actual referrals  | Increase from previous year |
|-------------------------------|---|-----------------------------|
| 2009/10                       | 172   |                             |
| 2010/11                       | 218   | +46 (26%)                   |
| 2011/12<br>(to 16 March 2012) | 166 (37/52 wks actual)<br><i>Estimate full year * 233</i> | <i>Est +15 (6%)</i>         |

\*estimate is based on average of current actual to 16 march 2012 multiplied by 52 weeks

Taupo Hospice has experienced a steady increase in the number of 'active' patients (people receiving care at any one time) due to people staying longer under hospice care (earlier referrals and/or people living longer with improved palliative intervention). This places pressure on the hospice resources.

Hospice services report that with the increasing referrals and 'active' patient numbers they are reprioritising activities. Clinical care is a priority and time for education, social support and other activities of holistic care is declining.

There is no data available to demonstrate workload volume or trends for generalist providers such as GPs, district nurses or allied health.

Internationally there is no consensus about population size or appropriate specialist-generalist service volumes for resourcing. Most research and policy development in this area originates in the UK and Australia where inpatient palliative care is more common than in New Zealand, and so, should be treated with caution in the New Zealand setting.

### Specialist palliative care inpatient beds

The *New Zealand Palliative Care Strategy* listed the number of palliative care beds in New Zealand in 1998/99 per 100,000 population. This ranged from 0.64 to 7.8 beds per 100,000 with an average of 4.3 beds per 100,000 population. Lakes DHB does not have any dedicated palliative care beds in the acute hospitals or community inpatient beds. Although there are no dedicated beds there is easy access to acute beds in general hospital services and access to residential care beds for people who are dying or who require respite.

Palliative Care Australia recommends 6.7 beds per 100,000 population, based on an 85% occupancy rate<sup>34</sup>. In Ireland, the recommended level in 2007 was 10 inpatient hospice beds per 100,000 population<sup>35</sup> however it is recognised that palliative care services in Ireland are more developed than other countries.

Table 16 provides a review of specialist inpatient palliative care beds against Australia and UK benchmarks. These figures have been widely referred to in literature on palliative care however they are

<sup>34</sup> Palliative Care Australia 2003. *Palliative Care Service Provision in Australia: A Planning Guide*. 2<sup>nd</sup> edition:

Palliative Care Australia

<sup>35</sup> Staffing Levels and Bed Numbers in Specialist Palliative Care in Ireland, 2007. Update of baseline study (2005) data. [http://www.hospice-foundation.ie/index.php?option=com\\_content&task=view&id=240&Itemid=157](http://www.hospice-foundation.ie/index.php?option=com_content&task=view&id=240&Itemid=157)

contingent on support from a well-managed community focus on delivery of palliative care. Also included is the NZ 1998/99 average beds per 100,000 population.

**Table 16: Required specialist inpatient beds per 100,000 population**  
using international benchmarks (rounded to whole number)

|                             |         | <b>Australia</b>       | <b>UK</b>              | <b>NZ</b>              |
|-----------------------------|---------|------------------------|------------------------|------------------------|
|                             |         | <b>6.7 per 100,000</b> | <b>5.1 per 100,000</b> | <b>4.3 per 100,000</b> |
| <b>Lakes DHB Population</b> |         |                        |                        |                        |
| 2006                        | 98,300  | 7                      | 5                      | 4                      |
| 2016 (projected population) | 104,900 | 7                      | 5                      | 5                      |

The requirement for beds is likely to vary depending on the demographic and socio-economic composition of the area and the discrepancies between countries is likely due to the way in which palliative care services are developed in each country. For example, the Netherlands and Italy have the lowest numbers of beds per population and both did not commence specialist palliative care until early to mid 1990's while 'hospice' care in Ireland dated back to the late 1800's and modern palliative care originated in London in 1967.

Palliative Care Australia suggests a minimum of 10 beds in a unit to ensure a critical mass of patients and staff with expertise. The economies of scale prohibit a dedicated hospice inpatient unit for Lakes DHB at this time. Therefore, it is important that the specialist palliative care services have good relationships and processes in place to access beds in:

- the local acute general hospitals when required for complex needs and that the admission process, care during stay and discharge planning happens in a coordinated and seamless way for the patient
- appropriate residential care facilities when required for short term respite or longer term residential care.

## Hospice Facilities

### • Taupo

The hospice operates from Hospice House on 7 Sunset St in the centre of Taupo township. This is the administration base for the hospice staff & volunteers. The visiting medical specialist clinics, day care programmes, 'Kowhai' bereavement group, various activities such as massage therapy and relaxation classes and palliative education programmes are provided from this location. Equipment is stored in a garage at this site.

Lake Taupo Hospice has been operating a weekly garage sale for many years from a garage located in Puriri Street, with a second garage being added in 2009. This was a very successful fundraising operation but several concerns were raised including the lack of space for the donated items, unpleasant places for the volunteers to work and impact the shoppers cars have on the residential neighbourhood.

After considerable research both locally and nationally the Lake Taupo Hospice Trust decided to open a Hospice shop. With assistance from local businessman Glyn Pointon, a location was secured in new premises being built in Totara St and the hospice shop opened in August 2011. Equipment previously stored at Hospice House has been relocated to the Puriri Street garages and alterations completed at Hospice House in late 2011 to provide additional office space for staff and volunteers.

The opening of the Hospice shop has proven to be very successful. Donations of goods and income from shop sales have exceeded expectations to the point where a separate incoming goods warehouse has been sourced, also with the help and support of the Pointon family.

The premises at Sunset Street are restricted from further development in size by the residential zoning regulations. It is estimated that the size of the premises at Sunset Street will be unsuitable

by 2015 based on current estimations of growth in demand for day programmes and administration space.

In 2011, expressions of interest were invited from all Aged Residential Care Facilities and Taupo Hospital to have a separate suite of designated 'hospice' beds within their facility for end of life and respite care. BUPA at Liston Heights has taken up this invitation with Lake Taupo Hospice. To progress this would require hospice to fully fund a designated number of beds whether occupied or vacant. This cost is prohibitive within current funding and this initiative has not proceeded further at this stage. Both parties are still open to discussion of this concept in the future and a memorandum of understanding is still on the table.

Alternative site options have been considered by the Hospice. For example Taupo Hospital, being located on a large site between Kiddle Drive and Kotare site, would open the possibility of a future model that looked like Ashburton or Hawera where the palliative care beds are in 'hospital'. Although Taupo Hospital does have suitable rooms, this concept is not part of the planned rebuild of the hospital facilities taking place over the next few years. Purchasing surplus DHB land off Kiddle Drive may have been an option, albeit an expensive one, for future expansion of Hospice facilities.

This plan has been superseded by an offer from the Taupo District Council for land surplus to requirements at the top of Spa Park and this has been accepted by hospice. The Taupo District Council has agreed in principle to a long term lease for the site and a working party has been formed with the aim of a purpose built facility by 2015, with scope for the development of inpatient beds if needed by 2025.

- **Rotorua**

The Hospice operates from a building situated lake side in Queen Elizabeth Hospital grounds, adjacent to the Rotorua business district. All hospice services and staff are based there with the exception of the Hospice shops which operate from 80 Pururu Street and 1134 Eruera Street, Rotorua. Equipment is stored on-site behind the main hospice building.

The hospice has an ongoing lease on the current site however, discussions with the landlord and investigations on the relocation of the hospice in the event of future development of the lake front have commenced. At this time there is no urgency to relocate the hospice and the Rotorua Community Hospice Board considers the current site and buildings will meet the hospices needs at least for the term of this plan. The Rotorua Community Hospice Trust has no future plans to develop a hospice inpatient unit.

## 6.6. Palliative care workforce

The increasing demand for palliative care services is an international phenomenon with recognised workforce issues. Improving the quality of health services depends on adequate levels and availability of appropriate trained workforce including the important group of volunteers.

Key issues for development of a sustainable workforce include:

- To ensure adequate staff levels to address the growing demand
- Staff recruitment and retention strategies
- To ensure a multidisciplinary team approach
- To have a focused approach to training and development of undergraduate, graduate and post graduate health professionals, health care assistants, volunteers, carers and families/whānau
- Promotion of palliative care approach and services to general health professionals and providers
- Promotion of cultural learning
- To address the needs of the palliative care workforce in rural areas
- To increase Māori palliative care workforce
- To provide support and supervision of the workforce

This section explores resource requirements for Lakes based on international recommendations. These relate to specialist palliative care services inclusive of allied health. There is no information available on which to base resource requirements for generalist palliative care services (e.g. district nurses, GPs, registered nurses in residential care).

In 2011, Health Workforce New Zealand published the results of a workforce service review<sup>36</sup> to develop a vision and model of palliative care service and workforce for 2020 in a context of increasing demand and limited funding. Included in the report was a calculation of workforce and patient ratios (medical and nursing FTEs per 1000 patients in 2008). In the review, Lakes is grouped with Waikato and Bay of Plenty DHBs as one of eight network groupings. The Waikato/Bay of Plenty/Lakes ratio of 21.6 FTEs per 1,000 patients was the second lowest (next to the upper South Island) of all eight regions. The range was 42.2 FTEs per 1,000 patients to 20.7 FTE per 1,000 patients.

Internationally there is no consensus about population size or appropriate specialist-generalist service volumes for resourcing palliative care services. Most research and policy development in this area originates in the UK, Ireland and Australia where inpatient palliative care is more common than in NZ and there are differences in the models of care. Therefore using overseas estimations should be treated with caution in the NZ setting. However, in the absence of agreed national benchmark standards in NZ, we have used the guidelines published by Palliative Care Australia in 2003.<sup>37</sup>

The planning guide provides population-based specialist palliative care clinical staffing guidelines to support an integrated palliative care system. There is some variation in the Australian model when applying it to the Lakes situation. The Australian guidelines do not provide for hands on nursing care in the community and relies on this being provided by generalist community nurses (not accounted for in the resource calculations). While Lake Taupo Hospice currently has a shared care model with district nurses (until 1 July 2012), the Rotorua Hospice community nursing team provides hands on care. Therefore a direct comparison of all nursing components will not be possible.

It is acknowledged that the current Lakes DHB resourcing and funding will not meet the staff level requirements stated. However the DHB and hospices can prioritise where scarce resources are allocated for development of palliative care services as funds become available.

The staff levels have been calculated in detail for the Lakes region as a whole using the Palliative Care Australia resource model applied to Lakes demographics as follows:

|                     |                              |
|---------------------|------------------------------|
| Acute hospital beds | = 193 (Rotorua 178/Taupo 15) |
| Population          | = 104,000 <sup>38</sup>      |

<sup>36</sup> Health Workforce New Zealand, *Palliative Care Workforce Service Review*, 2011  
<http://www.healthworkforce.govt.nz/our-work/workforce-service-reviews/palliative-care>

<sup>37</sup> Palliative Care Australia, *Palliative Care Service Provision in Australia: A Planning Guide 2<sup>nd</sup> Edition*, 2003

<sup>38</sup> Based on the population quoted in the Lakes DHB Annual Plan 23 June 2011. This is also similar to the Statistics NZ estimated population for 2016 which is 104,900.

Palliative care designated beds = 0

(Staff types with an arrow indicates the resource works across all settings)

**Table 17: Lakes DHB recommended palliative care staff requirements**

| Position                                  | Community based service   | Acute hospital consultative service | Palliative care designated bed | Total for Lakes region | Estimated Current FTE Lakes (excluding admin & management FTEs)                              |
|---|---------------------------|-------------------------------------|--------------------------------|------------------------|--|
| Palliative care specialist <sup>1</sup>   | ←                         | 1.56                                | →                              | 1.56                   | Links with Waikato specialist medical team for monthly clinics in Taupo and Rotorua          |
| Registrar                                 | ←                         | 1.04                                | →                              | 1.04                   | -  |
| Resident medical officer                  | -                         | -                                   |                                |                        |  |
| Liaison psychiatry                        | ←                         | 0.24                                | →                              | 0.24                   | Referral to mental health  |
| Nurse Consultant/specialists <sup>2</sup> | 1.04<br>2.08 <sup>3</sup> | 1.16                                |                                | 2.2<br>2.08            | Community teams:<br>Rotorua RNs 7 FTE / HCAs 4 FTE<br>Taupo 2.6 FTE                          |
| Discharge liaison <sup>4</sup>            | ←                         | 0.26                                | →                              | 0.26                   | Included in community team care coordination roles   |
| Psychology                                | 0.26                      | 0.15                                |                                | 0.41                   | Hosp. referral   |
| Social work                               | 0.52                      | 0.39                                |                                | 0.91                   | Rotorua - Links with DHB<br>Taupo Hospice appointed 0.6 social worker/counsellor (end 2011). |
| Bereavement support                       | 0.26                      | 0.15                                |                                | 0.41                   | Taupo – included in social work above<br>Rotorua included in nursing roles                   |
| Pastoral care                             | 0.26                      | 0.39                                |                                | 0.65                   | Community churches   |
| Speech therapy                            | 0.21                      | 0.31                                |                                | 0.52                   | Hosp. referral   |
| Dietitian                                 | ←                         | 0.21                                | →                              | 0.21                   | Hosp. referral   |
| Physiotherapy                             | 0.42                      | 0.31                                |                                | 0.73                   | Hosp. referral   |
| Occupational therapy                      | 0.42                      | 0.31                                |                                | 0.73                   | Hosp. referral   |
| Pharmacist                                | -                         | 0.39                                |                                | 0.39                   | Hosp. or community pharmacists   |
| Music, art therapist                      | 0.52                      | -                                   |                                | 0.52                   | Taupo 0.1 FTE massage therapist  |
|   |                           |                                     |                                |                        |  |
| Volunteers <sup>5</sup>                   | 1 per 65                  | 1 per 65                            | 1 per 65                       |                        |  |

Notes:

1. Specialist and registrar positions have both community and inpatient responsibilities.
2. Community and acute care consultation teams require consultant/specialist level nurses to act independently, provide consultation to primary carers and to coordinate, monitor and review patient care. Clinical nurses are senior nurses who work under the direction of the consultant/specialist.
3. The Australian model excludes the direct hands on care of community nurses. Rotorua Hospice community nurses and HCAs provide nursing and personal care in the patient's home. Taupo Hospice RNs provide night nursing support in patient's homes.
4. The Australian model indicates the discharge liaison could be included in a nursing or social work position
5. Based on recommendation for "process" volunteers (e.g. routine practical tasks)



## **Medical**

The analysis identifies that Lakes DHB requires around 1.5 FTE palliative medicine specialists working across all care settings (community, acute hospital consultative, palliative care dedicated beds); 1.0 FTE registrar and 0.2 FTE in liaison psychiatry.

Currently Lakes specialist palliative care services (hospices) source specialist palliative care medical input from Waikato DHB in the form of monthly clinics.

It is recommended, as funding comes available, that an increase of palliative medicine resource would enable:

- timely patient access to palliative medicine assessment, consultation and input to care planning due to increasing number of referrals of people with complex clinical needs
- development of the palliative care approach with other specialist services especially in the acute hospitals
- increased delivery of palliative care education programmes
- increased support for GP's in palliative care
- additional support for the 24 hour/7 day week palliative medicine acute on-call service for general practitioners, other specialists and for assistance and advice to the specialist palliative care nurse on-call services
- increased support to remote communities in terms of outreach clinics
- reduced risk if there is a resignation and to enhance coverage for leave.

It is recommended that the development of specialist medical resources be done in a collaborative way within Midland to maximise the opportunity for sharing knowledge and expertise within the region. It is envisaged that while palliative medicine specialists will be employed by particular DHBs or hospices, they will collaborate and provide support across organisational boundaries to enhance palliative medicine in the region. This would require palliative care medical staff to be credentialed by each of the DHBs across the region. Further work needs to be carried out to fully develop this concept.

There is an opportunity to use technology to improve access to specialist medical consultations throughout the region using videoconferencing. This was trialled recently between Waikato and Thames hospitals with a palliative care patient follow-up consultation and worked well. This would be dependent on access to appropriate videoconferencing equipment and facilities at suitable locations in Lakes.

In addition to strengthening the specialist palliative medicine resources in Lakes, sustainable solutions to address the issues of GP availability and out of hours cover, especially for rural Taupo areas, needs to be developed as a part of PHO initiatives to deliver on the Government's Primary Health Strategy.

## **Nursing**

The emphasis of the Australian model is on consultation and specialist level support to generalists /primary carers and to coordinate, monitor and review patient care and recommends a total of 3.1 FTE nurse specialist and clinical nurses in the community setting. This is similar to the role of specialist palliative care coordinator in the Lakes model and is similar to the model proposed in the Health Workforce New Zealand palliative care workforce service review.

If the future sustainability of specialist palliative care is dependent on increasing the capacity and capability of generalists to care for palliative people and their family/whānau, thus enabling specialist services to deal with more complex cases, then the provision of education is a critical role for specialist palliative care. The Hospice New Zealand Fundamentals of Palliative Care education package has recently been released and provides a nationally consistent tool for delivery of education across the multidisciplinary group of generalists. It has been developed with an aged care focus in the first instance but is intended to be modified for use with other groups such as practice nurses, hospital teams, Māori health providers.

The specialist services need to continue to develop education for these generalist groups in their region with timeframes and resources assigned. A commitment of support from the generalists employing organisation for release time and financial support, where required, should be considered as part of the planning process.

The *New Zealand Palliative Care Strategy* described specialist palliative care services as employing “a majority (over 60 percent) of their registered nursing staff with a recognised palliative care qualification and the rest working towards completed palliative care qualifications”. Currently Rotorua Hospice has 57 percent of RNs<sup>39</sup> with post graduate qualifications and Lake Taupo Hospice has 100 percent.

The Ministry of Health and the Nursing Council have identified palliative care as one of the scopes of practice for nurse practitioner role development in New Zealand. For a registered nurse to meet the Nursing Council criteria they must have a clinical masters degree, at least four years experience in palliative care and pass a Nursing Council assessment of competencies. Registration as a nurse practitioner with prescribing rights can also be obtained. Nurse practitioners are expert nurses, have advanced levels of assessment and treatment skills to manage complex situations, promote evidence based practice to influence standards in health practice and have the ability to order, conduct and interpret diagnostic and laboratory tests and administer therapies for the management of potential or actual health needs. The nurse practitioner role has the flexibility of practice to work across a large range of settings and has the potential to contribute significantly to service provision in rural areas where access to specialist medical support is limited.

A Lakes palliative care workforce plan should consider a pathway for development of a nurse practitioner in palliative care in conjunction with the DHB professional nurse development programme.

### **Allied health**

Allied health professionals are an essential component of a comprehensive and quality palliative care service. In Lakes, access to allied health services is through a centralised DHB model which is a common access model for palliative care services in New Zealand. As indicated earlier, it is recognised that nationally there is lack of formal training in palliative care for allied health professions and limited access to funding to support further training/education. The draft Resource and Capability framework recommends the development of a qualification appropriate for the allied health workforce to maximise the potential for discipline specific skill they bring to the provision of palliative care services.

### **Volunteers**

Hospices rely on the significant input of volunteers to support many of the services and fundraising efforts. Formal induction and training programmes are required on an ongoing basis for volunteers and are delivered regularly by the hospices.

### **Carers**

The important role of carers, especially in the home, is widely acknowledged. These are the family/whānau or other carers that are often with the patient, providing day to day care and support. There is a need to ensure they have an appropriate level of understanding and knowledge to support the patient and to be able to identify when help is needed and how to access help. Both specialist and generalist palliative care service providers have a role to play in education of carers and programmes and resources need to continue to be developed to support this learning.

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<sup>39</sup> The percentage of RNs is measured as a headcount of permanent nurses (not FTE or casual nurses).

## 6.7. Hospital based specialist palliative care

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The *New Zealand Palliative Care Strategy* describes hospital palliative care teams as necessary to educate and advise all hospital services on the palliative care approach and the need to provide palliative care as an option for people who are dying. They would also assist in ensuring people access the appropriate palliative care services in their communities on a timely basis.

Australian guidelines<sup>40</sup> suggest the availability of specialist palliative care practitioners within hospital and clinic settings is likely to increase the timeliness and rate of referral to palliative care services and to improve the symptomatic management of these people. They describe specific roles for palliative care in the acute setting as being:

- assessment, symptom management and consultation;
- discharge planning for all palliative people; and
- education of health care providers throughout the hospital.

Irish guidelines recommend a consultant-led multidisciplinary palliative care team in each acute hospital of 150 beds or more. Resourcing is recommended to include (as a minimum) a specialist palliative care nurse, a social worker and a secretary, led by the palliative medicine specialist working across the range of settings and who was available in the hospital for a defined minimum number of sessions per week. The guidelines suggest that for smaller general hospitals, where it may not be feasible to employ a full-time specialist palliative care team, the specialist palliative care team serving the community should provide a service to people in the hospital.

In Lakes DHB, the input of specialist palliative care in the acute hospitals is via the hospices as the contracted specialist palliative care providers for their local areas. Links are well established with the hospital services; hospice nurses participate in MDT and discharge planning meetings and are available to provide support to people and family/whānau in hospital. A key link for hospice to Rotorua Hospital is through the cancer co-ordinators - nurse specialists. The palliative medicine specialist visiting service from Waikato DHB is coordinated by the hospices who arrange clinics/consults which include palliative people in the community as well as hospital inpatients, as required.

Late referrals to Rotorua Hospice were identified as an issue during the stakeholder meetings. There is a need to continue to develop the visiting palliative medicine specialist service in Rotorua to fully integrate it with hospital services and provide education and support to hospital specialists and other hospital staff.

Opportunities to increase the formal involvement of specialist palliative care services (hospices) in the hospitals needs to be explored including access to diagnostic services and opportunities to provide palliative care education in the hospital.

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<sup>40</sup> Palliative Care Australia *Palliative Care Service Planning in Australia: A Planning Guide*, 2003

## 7. Summary of stakeholder feedback, strengths and issues

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In 2010 stakeholder meetings were held to obtain feedback on local services as input to the development of the service plan. In this section feedback and issues provided during the stakeholder consultation is included. However, it should be noted that considerable time has passed since the initial meetings and during this time progress has been made in a number of areas.

There were many comments of support for the palliative care services provided during the stakeholder meetings. A wide range of people who provide generalist and specialist level palliative care services in Lakes are acknowledged as being very dedicated and skilled, and display significant commitment to improving the quality of life for their people and their family/whānau/carers.

There is wide acknowledgement of the progress made to date in the DHB, particularly in the development of the specialist services and the work of the hospices. However there are gaps and issues that require ongoing attention.

A detailed SWOT analysis for each district is included in Appendix 10 and 11.

### 7.1. Stakeholder feedback

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In 2010, meetings were held at the hospices to gain feedback from stakeholders on how the current model of palliative care in the region was perceived to be meeting the local needs, to identify issues or concerns and areas that could be improved. There were also follow up discussions and/or teleconferences with specific groups to explore particular areas.

In general, there was very positive comment on the services delivered by the hospices in each district. They have formed strong partnerships with primary health care, residential care facilities and other supportive care services. The GP's and other organisations feel well supported by the hospices.

Key strengths of current specialist services are summarised.

- Single point of access and assessment by hospices as the specialist palliative care services in their districts.
- Coordination of care works well for people within the specialist services.
- Strong philosophy of home based care and support.
- Specialist services available 24/7.
- Dedicated and knowledgeable palliative care staff.
- Low staff turnover in the specialist palliative care services.
- Strong links with generalist services e.g. GPs, residential care, Lakes NASC, Kaitiaki nurses, Māori Health providers, Mental Health services.
- Strong community support for hospices (fundraising and volunteer resources).
- Well developed hospice facilities for service users and providers/staff.

#### **Stakeholder feedback - Rotorua**

The GPs value the knowledge base of the hospice nurses and availability of the 24/7 telephone support from the Waikato palliative care medical specialists (although a few indicated they were not aware of this medical advice service).

There was some discussion around the appropriateness of placing a person under 65 in an aged care facility and whether there is a more suitable place for them. The Ministry of Health has no current plans to look at this on a national basis. Although it is understood to be an issue when it arises, locally the numbers are low - about 30% of hospice people are under 65 years (in 2010 = 52 people) and the economies of scale would make it difficult to find an affordable/suitable solution e.g. hospice inpatient beds.

The residential care organisations commented on the desire to enhance the palliative support they provide for their residents and acknowledged the need to develop their staff palliative care knowledge and skills in order to do this. While the Rotorua hospice vision is to enhance the education opportunities they provide for others, this has been difficult with limited hospice resources for education. Also contributing to this is the high turnover of staff in residential care facilities.

A key issue identified was late referral to Rotorua Hospice and this became the subject of some considerable discussion.

- The Hospice believe many of the late referrals come from Rotorua Hospital where there is limited ability to have a close link with oncology as the oncologists are visiting specialists only. The cancer liaison nurses have a close link with oncologists and the hospice receives referrals from these nurses, but they are also often late referrals.
- Often people understand hospice as only supporting the last stage of life rather than being aware of the full range of services and support that can be offered for a person and family/whānau. "Sometimes people think they are not sick enough to need hospice". The vision of Rotorua Hospice is to educate generalists to encourage people to go the hospice earlier so the support and information can be offered to the patient and their family/whānau on a more timely basis (and not in crisis).
- It was identified that Maori often resist referral to hospice, believing that referral to hospice means "I am expected to die now" (this is typical of other ethnicities as well). This results in late referrals and can make it more difficult to respond to all needs as there is little time to build a trusting relationship and can complicate bereavement.

The hospice has built a strong relationship with Hunga Manaaki and Māori social workers and has found the best advocates for Māori, when it comes to promoting support from hospice, are those Māori whānau who have experienced the care that hospice provides. This advocacy has helped to change perceptions and promote the concept of hospice empowering and supporting the family/whānau to care for the patient at home, but for them to know how and where to get help when needed. Palliative care coordination, meeting people and whānau in person and attending MDT's at the hospital where all disciplines are represented, has also made a significant difference for the hospice. The relationship between Rotorua Hospice and Aroha Mai could be further developed.

### **Stakeholder feedback - Taupo**

The introduction of the end of life 'Liverpool Care of the Dying Pathway' (LCP) has improved end of life care in the hospital and community. Organisations that implemented LCP were positive. Previous problems with accessing medications and the need to contact GP's out of hours, in particular, were quoted as having improved greatly with the introduction of LCP.

The overall availability of grief and loss services and support in Taupo was considered to be good with these available via the hospice, in residential care facilities and from the local funeral directors. Some suggestions were made for further improvement:

- Increase the availability of men providing grief and loss support, especially for male family members/whānau.
- Don't forget to support staff that have a direct relationship with the patient. Self care for staff dealing with death is often missed in education.

Issues identified by stakeholders were:

- Access to hospice services 24/7
  - Hospice care co-ordinators are available Monday to Friday only – out of hours district nurses phone GPs or Waikato 24/7 telephone advice service. Some nursing backup in the weekends especially for syringe driver issues would be helpful.

- Future challenge for nursing will be after hours and on call/call outs if demand increases. May need to consider evening nurse (6 to 10pm shift) especially to manage post discharge support.
- Access to medication out of hours
  - The situation has improved since LCP was introduced with pre-emptive prescribing. However, emergency medication kits at Taupo hospital might be helpful. Currently district nurses go to the ward if they need medication (how often does this happen? Will hospice nurses need to be able to do this in the changed model from 1 July 2012?).
  - An issue exists for those people situated further out of Taupo e.g. Turangi which is 30 minutes travel, no rehome, GP after hours clinic or after hours pharmacy. An option may be a locked box at the person's home.
- End of life care & LCP
  - Medical cover in Taupo Hospital inpatient unit over weekends is often variable - MOSS/locum unfamiliar with LCP. *Notes (April 2012):*
    - *a review is currently under way to determine a suitable model of medical care and staffing for Taupo Hospital).*
    - *Following a recent case review the clinical director and clinical nurse director have met with emergency department medical staff and the LCP will now be started in ED when required.*
  - Gaining release time for LCP resource nurses to undertake LCP activities is difficult.
- Funding for end of life/residential care
  - Hospital level residential care beds are regularly full – perception is that there is a lack of beds (*although Planning and Funding advise a 75% occupancy rate*)
  - Different levels of funding for various stages of care and how to get good needs assessment on a timely basis
  - Lack of funding for long term palliative patient especially those under 65 years
  - Different funding models around the country – inconsistencies.
- Ambulance transport and cost issues
  - St John's Ambulance standard national policy is to charge for transporting to residential care facilities. There is no residential care facility in Turangi so people need to go to Taupo. If they cannot travel by normal transport the ambulance charge is \$395, paid for by the person. Same situation exists for Mangakino residents. This makes respite care inaccessible for people who cannot afford the cost of being transported to & from a care home.
  - Ambulance policy of transporting rural people to nearest hospital (e.g. Taupo or Tokoroa) causes delay and patient risk when it has been established that the person requires care at Waikato Hospital.
- Access to GPs out of hours - Turangi
  - No out of hours GP service in Turangi therefore high proportion of palliative people go to residential care in last stages.
  - If person is unwell after hours they go by ambulance to Taupo hospital. This increases demand on Taupo Hospital and impacts on the patient/family/whānau.
- Information
  - Local GPs use Medtech – Hospice can't access that so information is fragmented and duplicated.
  - A centralised note system would be good.
- Late referrals
  - On occasions referrals are received too late for hospice to be of best value for the person /family/ whānau.

## 7.2. Issues and gaps

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The following summarises issues and gaps identified during the plan development process. These are not presented in any priority order.

- Service level gaps mean access to essential services is variable.
  - Need to increase the presence of specialist palliative care (particularly medical) in Rotorua Hospital.
  - Lack of formalised access to specialist medical education in Rotorua.
  - There are gaps accessing suitable out of hours primary care support for some palliative people in the region (particularly Turangi)<sup>41</sup>.
  - Lack of suitable long term inpatient/residential care facilities for palliative people under 65 years of age.
  - Difficulty accessing medications especially after hours in more rural parts of Taupo.
- There are issues of access to palliative care services for people in remote rural areas. These are predominantly related to economies of scale for service provision and the socioeconomic status of people in these areas.
- There is a lack of clarity and understanding of roles, responsibilities and processes between some services. There is a lack of integrated patient information.
- Lack of palliative care approach and/or providers unsure of services available often results in late referral.
- There is inequitable access to home help, personal care and funded residential care beds.
- Funding of services is based on historical activities rather than assessed need and can perpetuate inequities. Funding is fragmented and difficult to identify. The method of funding general practice is not conducive to providing quality palliative care.
- There is need to develop and promote palliative care clinical guidelines and pathways for generalist services.
- There is a lack of quality standards and performance indicators for palliative care across the generalist providers (primary practice, residential care, district nurses and other providers) and specialist palliative care services. There is poor availability of information to understand or monitor the amount of palliative care provided by generalists.
- There is forecasted growth in referrals due to population growth and change in population characteristics, increasing incidence of cancer and nonmalignant diseases and increased awareness of palliative care services. Private and public funding to expand palliative care services is limited and therefore changes to current service delivery models will need to be considered for future sustainability.
- There is a need to continue to work closely with Māori to identify and reduce the cultural barriers for Māori accessing palliative care and to build mainstream service responsiveness to the needs of Māori.
- Workforce development and education across the whole continuum of care is viewed as a critical area for future sustainability of services.
  - There is under representation of Māori within the palliative care workforce.
  - It is difficult for generalists to maintain palliative care skills and up to date knowledge when the numbers of palliative people are small and/or the need occurs infrequently.
  - The high use of locum staff in hospital and community settings reduces local palliative care knowledge of services and pathways.
  - The access specialist services have to the hospitals to provide education is limited.

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<sup>41</sup> Note: The lack of primary coverage 24/7 is outside the scope of this plan.

- The role of allied health in the specialist service multidisciplinary teams is underdeveloped and limited by competing patient demands.
- People (and their family/whānau) who receive care from the hospices have access to grief and bereavement support. People who may not have a life limiting illness and/or have not received hospice care during illness can also be referred to the hospices for specialist grief and loss support. It is not known if this is understood in the community (by GPs etc) and if there is an unmet need (e.g. patients not being referred to the hospices for specialist grief and loss support who may benefit from it).



## 8. Vision and recommendations

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### 8.1 Vision

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This section provides specific actions for Lakes to 2016 using the framework provided in the draft report by the Palliative Care Council *Measuring What Matters: Palliative Care* (see Appendix 2 for the framework overview).

The updated national palliative care strategic vision is:

*All people who have a life limiting illness and their family whānau who could benefit from palliative care have timely access to quality palliative care that is culturally appropriate and provided in a coordinated way.*

Three long term outcomes are considered necessary to achieve the vision. These are indicated below along with the system outcomes that form the area of focus for the actions recommended in the Lakes palliative care service plan.

| Long term outcome  | Palliative Care System Outcome   |
|--|--|
| Access to palliative care regardless of setting                                | <ul style="list-style-type: none"><li>• Sufficient capacity within primary and specialist palliative care</li><li>• Appropriate referrals to specialist palliative care services</li></ul> |
| All palliative care providers are configured to ensure a seamless care pathway | <ul style="list-style-type: none"><li>• There is continuity and coordination of care</li></ul>   |
| Palliative care provision is high quality                                      | <ul style="list-style-type: none"><li>• Best practice is followed in delivering palliative care</li><li>• Palliative care meets the needs of patients, their families and whānau</li></ul> |

### 8.2 Recommendations

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#### Access to palliative care regardless of setting

##### **Ensure sufficient capacity within primary and specialist palliative care**

*Achieving this outcome requires sufficient workforce and appropriate services and infrastructure*

##### **Actions**

1. Continue to develop specialist medical palliative care visiting service for Rotorua Hospital and ensure it is fully integrated with the Rotorua community specialist palliative care service.
2. Regularly monitor utilisation and demand for palliative care medical specialist input to palliative care and education in Rotorua and Taupo with the lead provider, and anticipate required changes to meet local population need.
3. Review the composition of specialist palliative care multidisciplinary teams and how the specialist services access allied health support.

4. PHOs to develop and implement sustainable solutions which ensure all palliative people have access to a general practitioner 24/7 and ensure processes allow for the GP to be familiar with the patient's condition and care plan.
5. Develop a workforce plan to address identified areas of skill shortage in palliative care (specialist medical, allied, Māori in palliative care). This would include exploring the opportunities for further new roles in palliative care e.g. nurse practitioner and linking with wider Midland regional initiatives e.g. regional medical service development (hub and spoke concept) and the Lakes DHB professional nurse development programme.
6. Ensure access to clinical supervision to monitor and support nurses and allied staff who are providing palliative care.
7. Implement the Hospice NZ programme 'Fundamentals of Palliative Care' for identified groups starting with the residential care sector.
8. Implement cultural competency education for health professionals in specialist palliative care services where required.
9. Develop and implement topic specific education sessions for palliative care health professionals in caring for people with nonmalignant conditions and dementia.
10. PHOs to integrate palliative care into patient pathways/guidelines, education and training plans of primary practices.
11. Understand education and support needs for Māori health providers to inform palliative care education planning and service development.
12. Investigate alternative methods of service delivery to create efficiencies and improve access to care e.g. nurse led clinics; videoconferencing (including a scope of infrastructure support requirements); new roles to support rural areas. Use Lean Thinking methodology to identify and implement service delivery improvements.
13. Initiate a project to scope access to grief and loss/bereavement services in Lakes particularly for those people who are not referred to specialist palliative care services but who may benefit from grief and loss support. Identify any gaps and report to DHB planning and funding.
14. Review access to emergency/out of hour's medication and contribute to the development of a regional standard. Ensure all stakeholders understand how to access emergency/out of hours medication.
15. Contribute to the development of nationally consistent (or regional, where appropriate) palliative care access criteria, clinical guidelines and other resources where possible, and implement in Lakes where necessary.
16. Lake Taupo Hospice to plan and implement the transition of model of care from shared care with district nursing to hospice community nursing (implementation 1 July 2012). Identify risks and monitor changes to ensure continuity of care for palliative people in the community. Establish KPIs to measure and monitor service change. Undertake evaluation.
17. Plan for relocation of Lake Taupo Hospice specialist services to new site.
18. Work with NASC provider to ensure equity of access to home help, personal care and residential respite/end of life care based on need.

## **Ensure appropriate referrals to specialist palliative care services**

*Achieving this outcome requires awareness of palliative care referral processes and understanding of palliative care principles.*

### **Actions**

19. Improve timeliness of referrals by:
  - Developing specific written access criteria and referral processes for generalists (including community and hospital based generalists)
  - Developing the capability of GPs and hospital services to recognise and refer people to specialist palliative care services on a timely basis
  - Reducing barriers to referral through raising public awareness and understanding of palliative care.
20. Develop a Lakes palliative care service directory including service description, access criteria and referral processes. Communicate to stakeholders.
21. Review and strengthen website content of the DHB, hospices, Māori health providers, PHOs and other relevant NGOs to link with the service directory and clinical guidelines.
22. Develop and implement a communication plan for palliative care health promotion to increase public understanding of palliative care. Monitor and evaluate impact of actions.
23. Review and standardise palliative care patient/family/whānau information and ensure it is presented in an appropriate manner for target groups.
24. Ensure that hospitals and other PHO and NGO services have policies and protocols reflecting the palliative care approach.
25. Educate providers in the palliative care approach through the development of orientation and/or education sessions for:
  - general practice teams
  - residential care sector
  - Māori health providers
  - other NGOs and/or support groups
  - specialist/clinical services of the acute hospitals
  - community and allied health services
  - volunteers.

## **Support and align with national palliative care work programme priorities**

### **Actions**

26. Apply Resource and Capability Framework to the Lakes district and linking with the Midland region when published (estimated mid 2012).
27. Implement other national work programme initiatives as they become available i.e. service specifications and any new funding models.
28. Implement the HISO National Specialist Palliative Care Data and Business Process Standard when finalised.

## All palliative care providers are configured to ensure a seamless care pathway

### Ensure there is continuity and coordination of care

*Achieving this outcome requires integration throughout the health sector and services/providers to be coordinated with each other. This includes the need for*

- appropriate links between services
- appropriate role delineation between providers
- shared strategic vision across the region
- appropriate information sharing.

### Actions

29. Specialist services to strengthen relationships and support to local acute hospital services (also refer to #1).
30. Specialist palliative care services to actively engage with Midlands Health Network and Health Rotorua PHO as they plan and implement changes designed to meet the governments' primary health strategy 'Better, Sooner, More Convenient'
31. Develop and document service level agreements between specialist palliative care services and generalists who provide services for care of the palliative patient. Monitor to ensure continuity of care is maintained (also links with action #26).
32. Develop a process to ensure every palliative person has a nominated care coordinator and there is a plan for continuity of care after hours. A care coordinator is required for all palliative people not just those that access specialist palliative care services.
33. Complete the implementation of PalCare into hospices and scope PalCare system integration with (or access by) primary, hospital and other specialist services. Implement as agreed. Also consider interface with a regional data repository and shared care record.

## Palliative care provision is high quality

### Best practice is followed in delivering palliative care

*Achieving this outcome requires that standards for palliative care services are met; there is an interdisciplinary team approach to palliative care, and patient pathways are followed.*

### Actions

34. Implement the Hospice New Zealand Standards in hospices and hospital services (where relevant). Consider relevance of HNZ standards to other generalist services.
35. Complete implementation of Liverpool Care Pathway (LCP) in Lakes and monitor utilisation to ensure sustainability.
36. Implement the LCP reflective data cycle as the quality improvement cycle of LCP.
37. Encourage and promote research opportunities relevant to the Lakes palliative care population and services. Apply the learnings from current Midland palliative care research projects to Lakes services.
38. Scope and support the implementation of Advance Care Planning with primary and specialist services.

## **Palliative care meets the needs of palliative people, their families and whānau**

*Achieving this outcome requires culturally appropriate care, meeting the needs of specific population groups and effective treatments and support.*

### **Actions**

39. Carry out a stocktake/hui to understand education and support needs for Māori health providers in Lakes to inform the palliative care education planning and palliative care service development.
40. Support specialist palliative care services to carry out cultural audits of services. Develop and implement service improvement plans in conjunction with local Māori health services.
41. Participate in the development of national or regional clinical guidelines and standards that support a range of treatments and implement across Midland.
42. Develop relationships with other services for support with care of people with nonmalignant conditions, multiple co-morbidities and/or dementia, and to provide input into service planning of other services where palliative care is identified as a part of the care pathway.
43. Scope and explore strategies to improve transport of palliative people between providers.
44. Scope and implement kaupapa palliative care approach including initiatives to support carers to care for their whānau in the community.

### **Method of implementation**

This plan has a focus of 2011 - 2016. The Lakes Cancer and Palliative Care Forum will prioritise actions and develop an annual action plan to guide the implementation of these recommendations over the five years. There may be actions identified that require a specific project approach in which case an appropriate group will be established and/or project resource identified within the annual action plan.

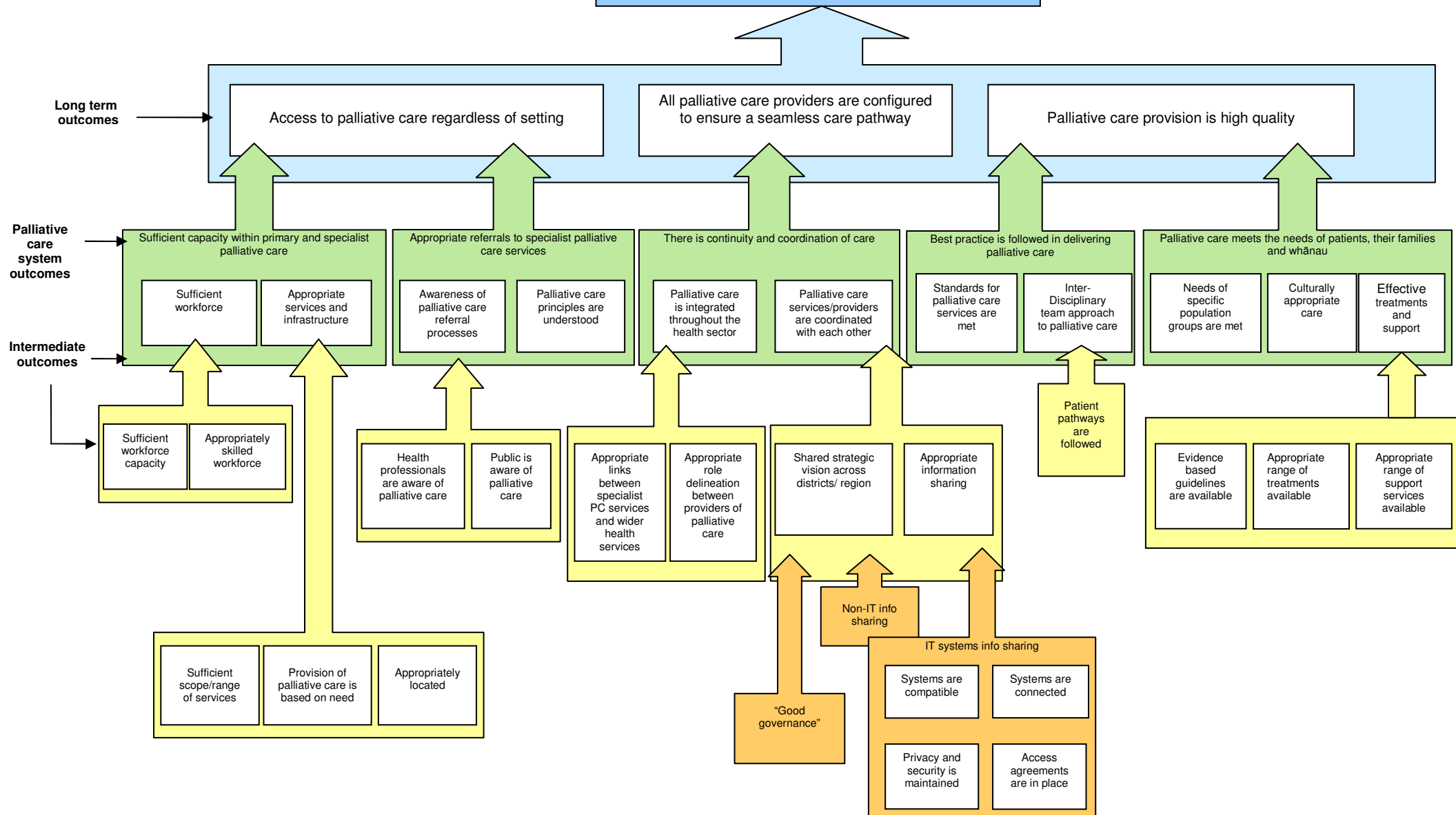
## NATIONAL DOCUMENTS / REVIEWS – ADDITIONAL DETAIL

| Title  | Summary  |
|--|--|
| <p><b><i>Report of the Palliative Care Expert Working Group to the Cancer Control Steering Group</i></b></p> <p>Ministry of Health: 2003</p> | <p>Recognised the implementation of the New Zealand Palliative Care Strategy had gone some way to increasing access to palliative care services. However, a number of remaining areas that required further action were identified. These were:</p> <ul style="list-style-type: none"> <li>• To continue to improve access to a defined set of essential palliative care services for people dying of cancer in each DHB</li> <li>• To ensure that a seamless service is provided for patients with cancer who require palliative care, no matter where they live</li> <li>• To ensure that the palliative care workforce continues to be developed so that it can meet the needs of current and future populations especially in relation to cultural diversity.</li> </ul>   |
| <p><b><i>Gap Analysis of Specialist Palliative Care in New Zealand</i></b></p> <p>Ministry of Health: December 2009</p>                      | <p>Provides an overview of the current provision of specialist palliative care services in New Zealand and highlights gaps against the draft service specifications. The gap analysis confirmed anecdotal evidence that there are wide variations in the provision of hospice and other specialist palliative care both at local and regional levels.</p>  |
| <p><b><i>Positioning Palliative Care in New Zealand</i></b></p> <p>Cancer Control New Zealand: Feb 2010</p>                                  | <p>Provided a review of Government Health Policy in relation to the provision of palliative care services in New Zealand.</p> <p>The report concluded that New Zealand was still some way behind other countries in recognising palliative care as an integral part of the health care continuum; and that while there was progress across the country in setting up palliative care services and in workforce development, there were still significant gaps. It also identified a lack of monitoring and evaluation of the strategy implementation.</p> <p>Remaining challenges:</p> <ul style="list-style-type: none"> <li>• Inequality of access; particularly based on diagnosis, but also in relation to ethnicity, age and geographic location</li> <li>• Lack/absence of data on population need, service provision and service utilisation</li> <li>• Lack of awareness/utilisation of palliative care services among the general public and health care professionals</li> <li>• Lack of inclusion in national health policy and strategic planning</li> <li>• Lack of a national strategic approach to research in palliative care.</li> </ul> <p>Seven recommendations were made to address what was considered to be a “relatively poor understanding of the need for palliative care and a lack of information on services currently being provided and how they are accessed by people with life limiting illnesses” (p. 18).</p> <p>The recommendations form a basis for the current work programme of the Palliative Care Council and will, over the next few years, provide further information to inform the development of palliative care services in NZ.</p> |

**Outcomes Framework – next page**

# **Palliative Care Strategic Vision**

All people who have a life limiting illness and their family/whānau who could benefit from palliative care have timely access to quality palliative care that is culturally appropriate and provided in a coordinated way.





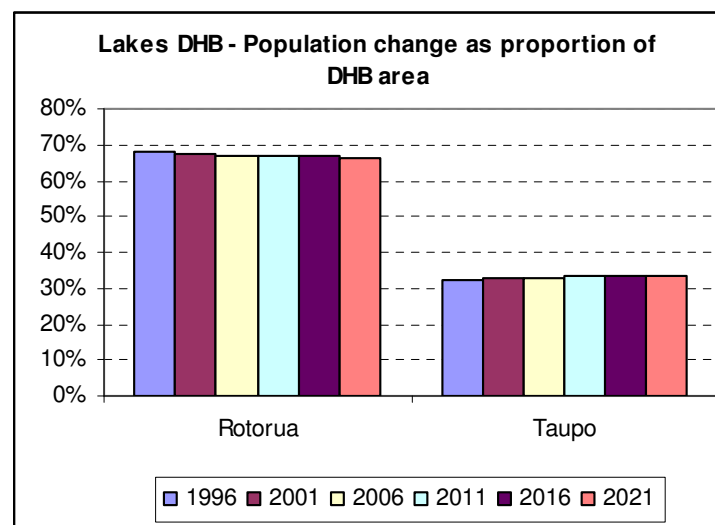
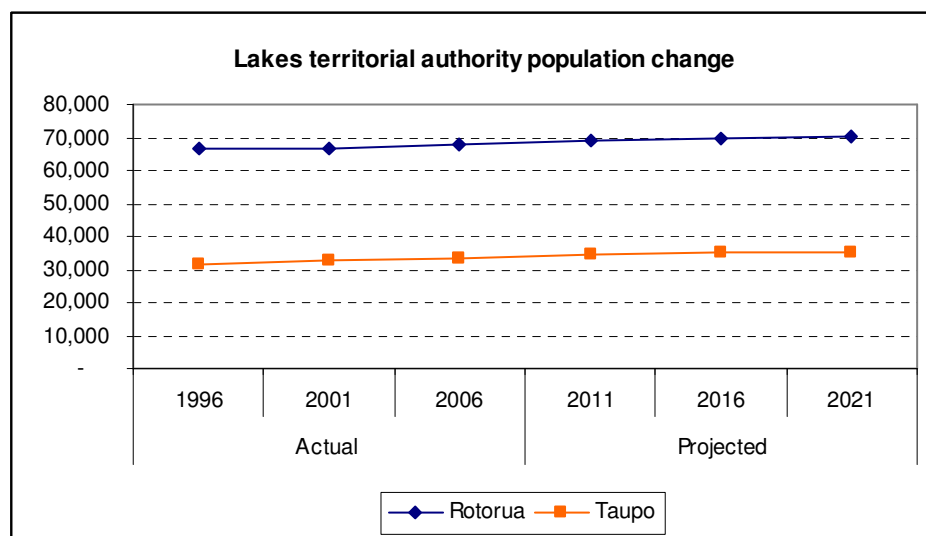
## 2006 Lakes Palliative Care review – actions and progress

|    | Recommendation   | Current status and progress made   |
|----|--|--|
| 1. | Formalised pathway to access palliative care physician services <i>That Lakes DHB purchase palliative specialist services from Waikato DHB and these services are fully integrated with the community hospices</i>   | <ul style="list-style-type: none"> <li>• Taupo - complete</li> <li>• Rotorua - complete</li> <li>• Access to 24/7 specialist medical phone advice complete.</li> </ul>   |
| 2. | Information - <i>That the palliative care coordinators develop written information on palliative care services and how to access them.</i>   | <p>Progress has been made.</p> <ul style="list-style-type: none"> <li>• Further opportunities for improvement exist with the development of a district palliative care directory.</li> </ul>   |
| 3. | Primary Care - <i>That PHOs provide information to hospices describing the palliative care service that is available through general practice and the criteria for access.</i>   | Achieved and ongoing<br>e.g. SIA funding   |
| 4. | Paediatric Palliative Care - <i>That Lakes DHB Planning and Funding work with the group formed to provide direction and coordination of a multidisciplinary team approach for children with life limiting condition, including the palliative care process.</i>  | <p>Completed through Kowhai Kidz programme but work of the group needs some refreshing increase active participation.</p> <p><i>Issues for paediatric palliative care will be addressed in a separate Midland plan for paediatric palliative care.</i></p>   |
| 5. | Improve access to palliative care in rural areas - <i>Investigate ways of improving access to palliative services in rural areas including the provision of more outreach services, establishing a team of rural based support workers in palliative care, and increasing collaboration of health and disability support providers in rural areas.</i> | <ul style="list-style-type: none"> <li>• Progress has been made on organising services and support for rural people /family/whānau and primary care.</li> <li>• Education programmes to upskill carers have been implemented.</li> <li>• Isolated problems will still arise and be dealt with on an individual basis.</li> <li>• Both hospices developed closer links to Health Reporoa nursing service and will take the lead in providing palliative care.</li> <li>• Recent issues with district nursing resource to support community palliative care and 24/7 availability in Taupo/ Turangi have led to a change in service model. DNs will exit palliative care contract and Taupo Hospice will provide the 24/7 community palliative care nursing from 1 July 2012.</li> <li>• Boundary maps updated.</li> </ul> |
| 6. | Education and training - <i>Work with the local Hospices and the Waikato DHB Palliative Care team to develop education to general practice, residential care facilities, support workers and carers, as well as hospital staff including emergency department staff.</i>   | <p>Taupo - significant improvement in:</p> <ul style="list-style-type: none"> <li>• increased dedicated education resource</li> <li>• increased programmes for generalists and carers</li> <li>• medical education via visiting specialist</li> <li>• Palliative care grand round videoconference link from Waikato Hospital</li> <li>• LCP training</li> </ul> <p>Rotorua – Some improvement in:</p> <ul style="list-style-type: none"> <li>• Education resource</li> <li>• range of programmes esp to residential care</li> <li>• LCP training</li> <li>• There remains a need for the hospice to gain more access to education</li> </ul>   |

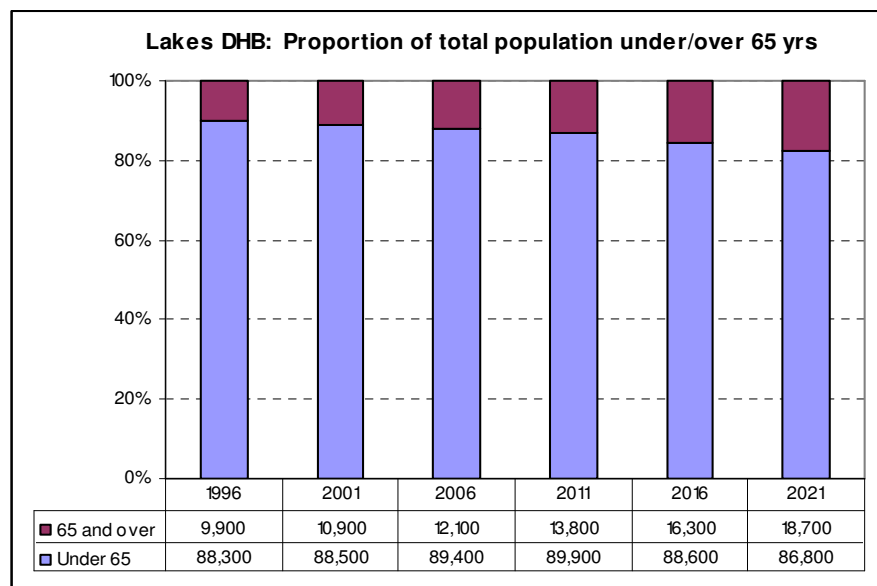
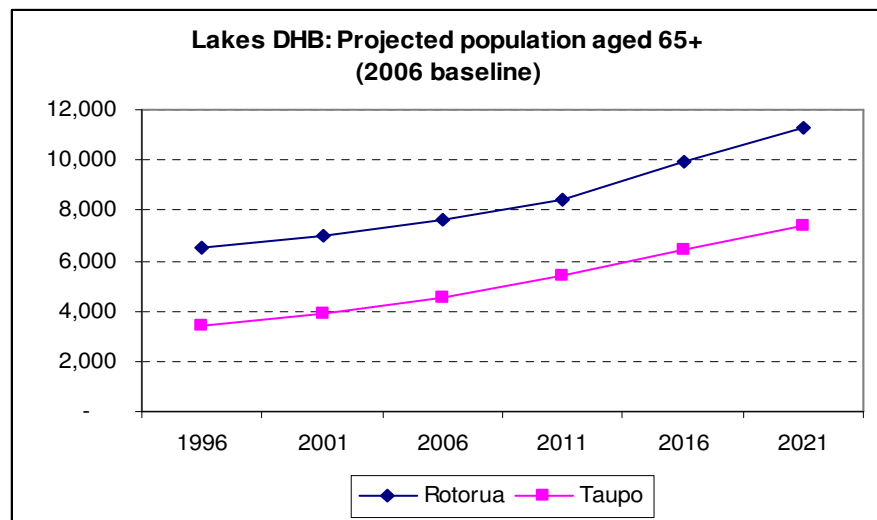
|    |  | opportunities with hospital staff  |
|----|--|--|
| 7. | Access to palliative care services for Maori - <i>Work with Māori service providers and Lakes DHB Iwi Governance group to develop a range of palliative care services for Māori. Continue monitoring statistical data showing the utilisation of palliative care service by Māori.</i> | <p>Statistics are provided by the hospices in quarterly performance monitoring returns to Planning and Funding. Both hospice's statistics indicate good coverage for Māori, both are well established in communities and well recognised. The community model supports whānau to look after people at home.</p> <p>Taupo Hospice works closely with Tuwharetoa iwi governance and has a strong presence at local marae. A Tuwharetoa representative is a member of the hospice board.</p> <p>Rotorua Hospice does not have strong links with iwi governance.</p> <p>Lakes has a Cancer Support team - Aroha Mai that works with palliative clients and Rongoa services that also focus on this group - who also get referrals from GPs. Hunga Maanaki team also work closely with Aroha Mai. Aroha Mai has MoU with provider arm to access people in hospital. Also provides support during treatment, terminal and after death.</p> <p>Both hospices aware of other Maori service providers but model of care is based on close links with persons GP &amp; whānau. Building on current relationships with Māori service providers needs to be ongoing.</p> |
| 8. | Palliative care for people with non malignant diseases - <i>Work with the local hospices and other relevant health providers to understand the role of palliative care in the non-malignant disease process.</i>   | <p>Both hospices promote services to non malignant client group - numbers of referrals are increasing.</p> <p>Further work is required e.g. discussion on when is it necessary for specialist palliative care and is there anything that hospice provides that is duplication of what a generalist palliative care organisation can/should do.</p>   |
| 9. | Improve the provision of palliative care to people in hospital services - <i>Work with the Lakes DHB hospitals and the local hospices to improve the provision of palliative care to people in the hospital services.</i>  | <p>Developing but further opportunity for improvement. Achievements include:</p> <ul style="list-style-type: none"> <li>• LCP implemented in Taupo and Rotorua hospitals</li> <li>• Visiting medical specialist in Taupo &amp; Rotorua available for hospital patients</li> <li>• Taupo &amp; Rotorua specialist palliative care nurses participate in hospital MDT &amp; discharge planning meetings</li> </ul> <p>Further opportunities:</p> <ul style="list-style-type: none"> <li>• visiting palliative care medical specialist integrated into hospital services, referral pathways &amp; clinical guidelines developed and implemented.</li> </ul>   |

## Lakes: Population Trends

|                        | Actual        |               |                | Projected      |                |                | % change     |
|------------------------|---------------|---------------|----------------|----------------|----------------|----------------|--------------|
|                        | 1996          | 2001          | 2006           | 2011           | 2016           | 2021           | 2011-2016    |
| Rotorua                | 66,600        | 66,900        | 68,100         | 69,200         | 69,900         | 70,100         | +1.0%        |
| Taupo                  | 31,600        | 32,500        | 33,400         | 34,400         | 35,000         | 35,400         | +1.7%        |
| <b>Total Lakes DHB</b> | <b>98,200</b> | <b>99,400</b> | <b>101,500</b> | <b>103,600</b> | <b>104,900</b> | <b>105,500</b> | <b>+1.3%</b> |



## Lakes DHB region : AGE



| Rotorua           |               |               |               |               |               |               |
|-------------------|---------------|---------------|---------------|---------------|---------------|---------------|
|                   | 1996          | 2001          | 2006          | 2011          | 2016          | 2021          |
| Under 65          | 60,100        | 59,900        | 60,500        | 60,800        | 60,000        | 58,800        |
| 65 +              | 6,500         | 7,000         | 7,600         | 8,400         | 9,900         | 11,300        |
| <b>Total</b>      | <b>66,600</b> | <b>66,900</b> | <b>68,100</b> | <b>69,200</b> | <b>69,900</b> | <b>70,100</b> |
| % under 65 yrs    | 90%           | 90%           | 89%           | 88%           | 86%           | 84%           |
| % 65 yrs and over | 10%           | 10%           | 11%           | 12%           | 14%           | 16%           |

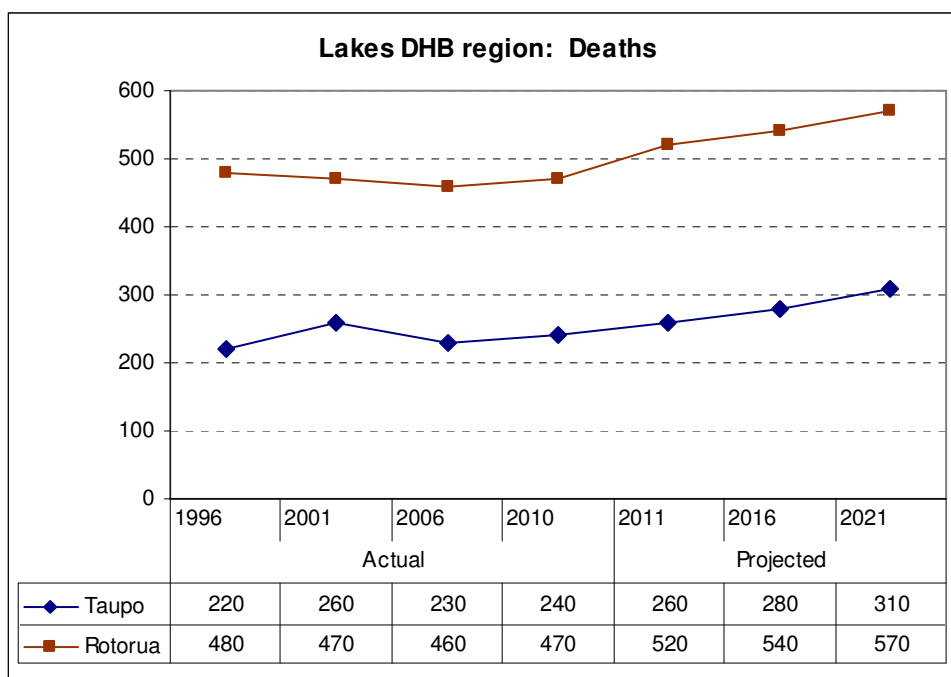
| Taupo             |              |              |               |               |               |               |
|-------------------|--------------|--------------|---------------|---------------|---------------|---------------|
|                   | 1996         | 2001         | 2006          | 2011          | 2016          | 2021          |
| Under 65          | 28200        | 28600        | 28,900        | 29,100        | 28,600        | 28,000        |
| 65 +              | 3400         | 3900         | 4,500         | 5,400         | 6,400         | 7,400         |
| <b>Total</b>      | <b>31600</b> | <b>32500</b> | <b>33,400</b> | <b>34,500</b> | <b>35,000</b> | <b>35,400</b> |
| % under 65 yrs    | 89%          | 88%          | 87%           | 84%           | 82%           | 79%           |
| % 65 yrs and over | 11%          | 12%          | 13%           | 16%           | 18%           | 21%           |

| ALL LAKES         |               |               |                |                |                |                |
|-------------------|---------------|---------------|----------------|----------------|----------------|----------------|
|                   | 1996          | 2001          | 2006           | 2011           | 2016           | 2021           |
| Under 65          | 88,300        | 88,500        | 89,400         | 89,900         | 88,600         | 86,800         |
| 65 and over       | 9,900         | 10,900        | 12,100         | 13,800         | 16,300         | 18,700         |
| <b>Total</b>      | <b>98,200</b> | <b>99,400</b> | <b>101,500</b> | <b>103,700</b> | <b>104,900</b> | <b>105,500</b> |
| % under 65 yrs    | 90%           | 89%           | 88%            | 87%            | 84%            | 82%            |
| % 65 yrs and over | 10%           | 11%           | 12%            | 13%            | 16%            | 18%            |

## Lakes – Deaths

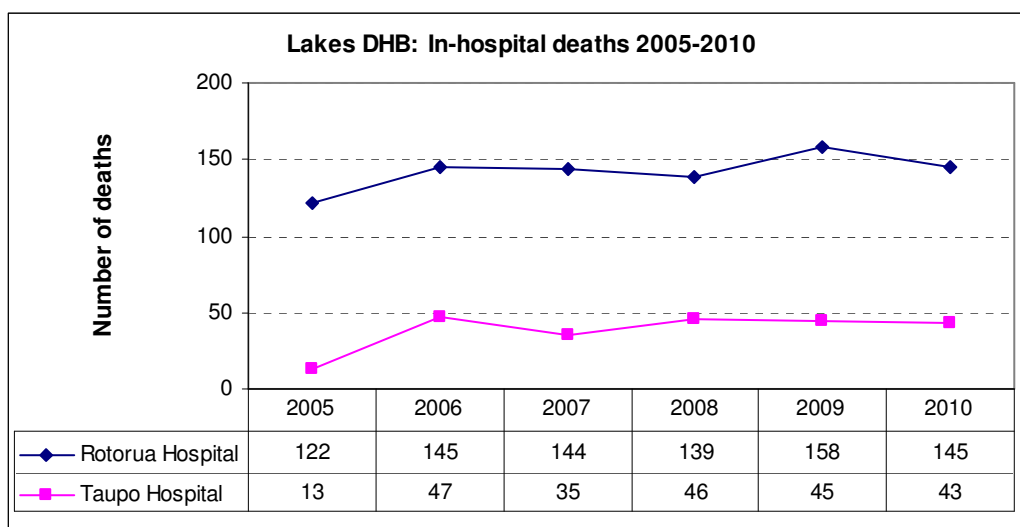
|         | Actual     |            |            |            | Projected  |            |            | % change  |            |
|---------|------------|------------|------------|------------|------------|------------|------------|-----------|------------|
|         | 1996       | 2001       | 2006       | 2010       | 2011       | 2016       | 2021       | 2011/16   | 2011/21    |
|         |            |            |            |            |            |            |            |           |            |
| Taupo   | 220        | 260        | 230        | 240        | 260        | 280        | 310        | 8%        | 19%        |
| Rotorua | 480        | 470        | 460        | 470        | 520        | 540        | 570        | 4%        | 10%        |
|         | <b>700</b> | <b>730</b> | <b>690</b> | <b>710</b> | <b>780</b> | <b>820</b> | <b>880</b> | <b>5%</b> | <b>13%</b> |



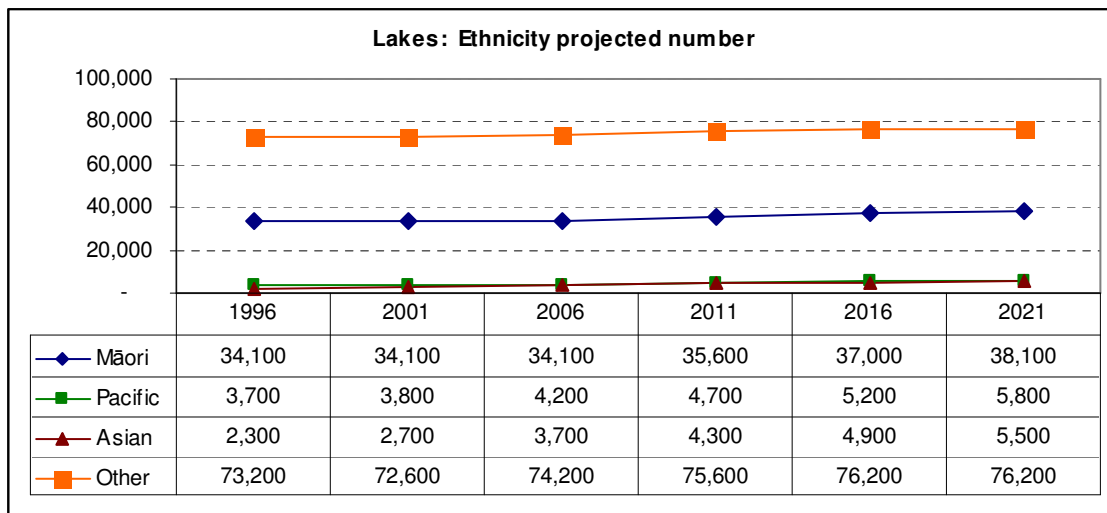
## Hospital Deaths

| Hospital               |  | Calendar Year |            |            |            |            |            | Total       |
|------------------------|--|---------------|------------|------------|------------|------------|------------|-------------|
|                        |  | 2005          | 2006       | 2007       | 2008       | 2009       | 2010       |             |
| ROTORUA                | AT&R (Under 65)  |               |            |            | 3          | 1          |            | 4           |
|                        | AT&R 65 & Over   | 1             | 4          | 2          | 1          | 6          | 5          | 19          |
|                        | Elderly Acute Medicine   |               |            |            | 1          |            |            | 1           |
|                        | Emergency Medicine   |               | 1          |            |            | 1          | 1          | 3           |
|                        | General Medicine   | 88            | 106        | 101        | 100        | 108        | 105        | 608         |
|                        | General Surgery  | 22            | 28         | 23         | 27         | 30         | 27         | 157         |
|                        | Inpatient Acute Mental Health                                    |               |            | 1          |            |            |            | 1           |
|                        | MIG Delivery   |               |            | 1          |            |            |            | 1           |
|                        | MIG Paediatric Neonatal Special/ Intensive Care (InActive NZHIS) | 2             | 1          |            | 1          | 1          |            | 5           |
|                        | MIG Physical Rehabilitation                                      |               |            | 2          |            |            |            | 2           |
|                        | MIG Well Newborns  |               |            | 1          | 1          |            |            | 2           |
|                        | Neonatal Intensive Care  |               |            |            |            |            | 1          | 1           |
|                        | Orthopaedic Surgery  | 7             | 3          | 10         | 3          | 4          | 1          | 28          |
|                        | Otorhinolaryngology (ENT)  |               |            | 1          |            | 1          |            | 2           |
|                        | Paediatric Medicine  | 1             | 1          | 2          | 1          | 2          |            | 7           |
|                        | Psychogeriatric A, T & R   |               | 1          |            |            |            | 1          | 2           |
|                        | Surgical Endoscopy   | 1             |            |            | 1          |            |            | 2           |
|                        | Well Baby - Community Lead Carer                                 |               |            |            |            | 1          | 2          | 3           |
|                        | Well Baby - Hospital Team Care                                   |               |            |            |            | 3          | 2          | 5           |
|                        | <b>Rotorua Hospital</b>  | <b>122</b>    | <b>145</b> | <b>144</b> | <b>139</b> | <b>158</b> | <b>145</b> | <b>853</b>  |
| TAUPO                  | AT&R 65 & Over   |               | 1          |            | 1          | 2          |            | 4           |
|                        | Emergency Medicine   |               | 1          |            |            | 2          | 3          | 6           |
|                        | General Medicine   |               | 45         | 35         | 45         | 41         | 40         | 219         |
| <b>Taupo Hospital</b>  |  |               | <b>47</b>  | <b>35</b>  | <b>46</b>  | <b>45</b>  | <b>43</b>  | <b>229</b>  |
| <b>LAKES DHB Total</b> |  |               | <b>192</b> | <b>179</b> | <b>185</b> | <b>203</b> | <b>188</b> | <b>1082</b> |

Sourced 24 August 2011



## Lakes: Ethnicity



Note: Above totals for ethnicities do not add up to total population. In the NZ Census people can elect to identify as more than one ethnicity.

## Service description summary for Lake Taupo Hospice

Prepared April 2012

|                                   |  |
|-----------------------------------|--|
| <b>DHB</b>                        | <b>Lakes</b>   |
| <b>Hospice</b>                    | <b>Lake Taupo Hospice Trust</b>  |
| <b>Description</b>                | Taupo Hospice provides a single point of entry specialist palliative care service in the Lake Taupo region. The model of care is care co-ordination provided by the hospice with nursing visits provided via links with the district nursing service.  |
| <b>Population Served</b>          | Population base at 2006 census: 32,418<br><i>Estimated population at 2006 census updated for residents missed, those temporarily overseas etc = 33,400)</i><br>Geographical area covers Taupo, Turangi, Mangakino and surrounds.   |
| <b>Population characteristics</b> | Taupo is one third of the total DHB population but covers 73% of the DHB geographical area<br>Area includes remote rural locations with high socioeconomic deprivation<br>Around 28% Māori<br>Population predicated to increase by 1.7% (600 ) between 2011 and 2016<br>Increasing proportion of 65 years and over <ul style="list-style-type: none"> <li>• 2006 = 13% of total (actual)</li> <li>• 2016 = 18% of total (predicted)</li> </ul>   |
| <b>Services</b>                   | <p>Nursing:</p> <ul style="list-style-type: none"> <li>• Palliative care co-ordination, initial and ongoing assessments</li> <li>• Community palliative care nursing via the district nursing service until 30 June 2012</li> <li>• From 1 July 2012, 24/7 community palliative care will be provided by the hospice nursing team</li> <li>• Night nursing (in home)</li> <li>• Coordinate placement in residential care beds for respite or end of life care &amp; access to home support and community support services</li> </ul> <p>Medical:</p> <ul style="list-style-type: none"> <li>• 24/7 medical telephone advice provided by palliative care medical specialists from Waikato.</li> <li>• Monthly palliative care medical specialist clinic (visiting service from Waikato). This also includes in-home visits where required and education of GPs. GP remains lead for people.</li> </ul> <p>Day programmes:</p> <ul style="list-style-type: none"> <li>• Tuesday club social networking and activities, art and craft group, massage therapy</li> </ul> <p>Equipment loan:</p> <ul style="list-style-type: none"> <li>• Short and long term loan of equipment to support care at home</li> <li>• Some examples electric beds, pressure mattresses, commodes, bath lifters, wheelchairs, Lazyboy chairs, car seat swivels</li> </ul> <p>Family support:</p> <ul style="list-style-type: none"> <li>• Grief and bereavement counselling and pastoral care</li> <li>• Carer relief</li> <li>• Social work</li> <li>• Carer support education</li> </ul> <p>Volunteer support services:</p> <ul style="list-style-type: none"> <li>• e.g. home visitors, complimentary therapists, beauty therapists, biographers, podiatrist,</li> </ul> |



|   |  |
|---|--|
|   | <p>transport/drivers, legal advisor, home cooking, administration support</p> <p>Education:</p> <ul style="list-style-type: none"> <li>• Syringe driver</li> <li>• LCP education and resource nurse group</li> <li>• Orientation to Hospice and palliative care</li> <li>• Video link to Waikato DHB Palliative Care Grand Round lectures</li> <li>• Fundamentals of Palliative Care workshop series</li> <li>• Health care assistant study days</li> <li>• Access to Genesis Oncology Trust breakfast lectures</li> <li>• Caregiver education</li> <li>• Public education via invited speaking engagements</li> <li>• Ad hoc education for generalists on request</li> </ul> <p>The hospice has access to reshome beds for end of life or respite when required.<br/>The need for short term respite residential care is low because normally people are supported at home using volunteers and/or night nurse via hospice.</p> |
| <b>Workforce</b>                              | <p>Lake Taupo Hospice has a total paid workforce of 8 headcount / approx 4.7 FTE as at March 2012. In addition, there is a group of casual &amp; relieving nurses and contracted medical service from Waikato.</p> <p>This is comprised of :</p> <ul style="list-style-type: none"> <li>• Administration 0.6 FTE</li> <li>• Clinical nurse specialists / registered nurses 2.6 FTE plus casual &amp; relieving pool (approx 0.2 FTE p.a.)</li> <li>• Volunteer manager &amp; day activities coordinator 0.8 FTE</li> <li>• Counsellor/social worker 0.6 FTE</li> <li>• Massage therapist 0.1 FTE</li> </ul> <p>Contracted service – medical specialist from Waikato 1 day per month (approx 0.05)</p> <p>Volunteers – Around 100 volunteers contribute approx 5000 hours per annum. They are considered an integral part of the efficient functioning of Taupo Hospice.</p>  |
| <b>LCP</b>                                    | <p>Taupo Hospice is the lead organisation for implementation of end of life Liverpool Care Pathway in the Taupo region. Implementation into all sites has been completed.</p>  |
| <b>Information/patient management systems</b> | <p>Lake Taupo Hospice has historically managed patient data using excel spreadsheets and paper based system. Implemented PalCare in 2011 as a part of a regional initiative lead by Waipuna Hospice.</p>   |
| <b>Quality standards</b>                      | <p>Pilot site for Hospice New Zealand Standards audit<br/>HealthShare audit<br/>QPS Benchmarking (voluntary participation - currently 25 NZ hospices participate)</p>  |
| <b>Key Linkages</b>                           | <p>Local and Lakes:</p> <ul style="list-style-type: none"> <li>• General practice teams and PHO teams incl nurse practitioners in Turangi/Mangakino</li> <li>• Community pharmacies</li> <li>• Taupo residential care providers</li> <li>• Taupo and Rotorua hospital services incl Te Oranga and Rotorua cancer nurse specialists</li> <li>• BOP DHB Planning and Funding, district nurses, physiotherapists, occupational therapists</li> <li>• Māori health providers</li> <li>• Cancer Society and other support groups</li> </ul> <p>Regional/national:</p>   |

- Hospices in other DHBs
- Midland Palliative Care Work Group
- Midland Cancer Network
- Hospice New Zealand

### Lake Taupo Hospice – Patient demographics

|           |   | 2007    | 2008    | 2009    | 2010    |
|-----------|---|---------|---------|---------|---------|
| <b>1</b>  | <b>Patients</b>   |         |         |         |         |
|           | Total patient numbers (deaths & transfers)                  | 106     | 113     | 103     | 100     |
|           | Deaths  | 85 80 % | 88 77 % | 92 89 % | 88 88 % |
|           | Transfers   | 21 20 % | 25 23 % | 11 11 % | 12 12 % |
|           | Active patients – avg per month                             | 30      | 32      | 35      | 37      |
| <b>2</b>  | <b>Age</b>  |         |         |         |         |
|           | Average age (years)   | 72.8    | 73.4    | 71.1    | 72.6    |
|           | < 65yrs   | 24 23 % | 31 27 % | 33 32 % | 25 25 % |
|           | 65 yrs and over   | 82 77 % | 82 73 % | 70 68 % | 75 75 % |
| <b>3</b>  | <b>Gender</b>   |         |         |         |         |
|           | Male  | 60 56 % | 53 46 % | 55 53 % | 58 58 % |
|           | Female  | 46 44 % | 60 54 % | 48 47 % | 42 42 % |
| <b>4</b>  | <b>Ethnicity</b>  |         |         |         |         |
|           | European  | 67 63 % | 74 65 % | 79 77 % | 80 80 % |
|           | Maori   | 20 19 % | 35 31 % | 22 21 % | 19 19 % |
|           | Other   | 19 18 % | 4 4 %   | 2 2 %   | 1 1 %   |
| <b>5</b>  | <b>Number of deaths</b>                                     |         |         |         |         |
|           | Taupo Hospice patients                                      | 85      | 88      | 92      | 88      |
|           | Taupo district (from Statistics NZ)                         | 260     | 250     | 250     | 240     |
|           | Percent   | 33%     | 35%     | 37%     | 37%     |
|           | Taupo Hospice patients in Taupo hosp                        |         | 17      | 14      | 13      |
|           | Taupo Hospital  |         | 46      | 43      | 40      |
|           | Percent   |         | 37%     | 33%     | 33%     |
| <b>6</b>  | <b>Place of Death (deaths and discharges)</b>               |         |         |         |         |
|           | Home  |         | 49 56 % | 52 57 % | 48 55 % |
|           | Hospital  |         | 19 22 % | 17 18 % | 18 20 % |
|           | Care Home<br>(includes those where the ARC is their 'home') |         | 20 23 % | 23 25 % | 21 24 % |
|           | Other   |         |         |         | 1 1 %   |
| <b>7</b>  | <b>Diagnosis</b>  |         |         |         |         |
|           | Cancer  | 65 61 % | 77 68 % | 81 79 % | 63 63 % |
|           | Non cancer  | 41 39 % | 36 32 % | 22 21 % | 37 37 % |
| <b>8</b>  | <b>Length of Stay (days)</b>                                |         |         |         |         |
|           | Average all patient   | 95      | 111.3   | 105.6   | 96.4    |
|           | Average LOS cancer (283 patients total)                     | 124     | 109     | 112     | 120     |
|           | Average LOS non cancer* (130 pts total)                     | 46      | 50      | 56      | 57      |
| <b>9</b>  | <b>Number of assessments</b>                                |         |         |         |         |
|           | Initial assessments - total                                 | 97      | 100     | 98      | 88      |
|           | Ongoing assessments - total                                 | 721     | 620     | 1024    | 1082    |
|           | Average assessments per patient                             | 7.7     | 6.4     | 10.9    | 11.7    |
| <b>10</b> | <b>Residential bed days (respite and EOL)</b>               |         |         |         |         |
|           | Number of patients  | 26      | 26      | 28      | 17      |
|           | Total days  | 391     | 454     | 479     | 285     |
|           | Average bed days per patient                                | 15      | 17.5    | 16.5    | 16.8    |

Source: Ministry of Health monitoring returns

\* LOS has been adjusted to exclude 3 significant outliers

## Service description summary for Rotorua Community Hospice

Prepared April 2012

|                                   |  |
|-----------------------------------|--|
| <b>DHB</b>                        | <b>Lakes</b>   |
| <b>Hospice</b>                    | <b>Rotorua Community Hospice</b>   |
| <b>Description</b>                | Rotorua Community Hospice provides a single point of entry specialist palliative care service in the Rotorua district. The model of care is assessment, care co-ordination and clinical nursing service provided by the hospice.   |
| <b>Population Served</b>          | <p>'Usually resident' population base at 2006 census: 65,901<br/> <i>Estimated population at 2006 census updated for residents missed, those temporarily overseas etc = 68,100</i></p> <p>Geographical area (2615 sq km) covers as far south as Waikato River, as far west as Mamaku, Kaharoa, Atiamuri, Waikite Valley, Ngakuru, as far east as Lake Rotoma and Kaingaroa and north of Okere Falls.</p>   |
| <b>Population characteristics</b> | <p>Rotorua is two thirds of the DHB population and only 27% of the DHB geographical area.<br/>         Around 35% Māori<br/>         Population predicated to increase by 1% (700) between 2011 and 2016<br/>         Increasing proportion of 65 years and older</p> <ul style="list-style-type: none"> <li>• 2006 = 11% of total (actual)</li> <li>• 2016 = 14% of total (predicted)</li> </ul>  |
| <b>Services</b>                   | <p>Nursing:</p> <ul style="list-style-type: none"> <li>• Palliative care coordination , initial and ongoing assessments</li> <li>• Community specialist palliative care nursing 24/7</li> <li>• Coordinate placement in residential care beds for short term respite or end of life care</li> <li>• Manage funding of this service directly with residential care facilities</li> <li>• Personal care in patient's homes</li> <li>• NASC assessments for long term care and home help</li> </ul> <p>Medical:</p> <ul style="list-style-type: none"> <li>• 24/7 medical telephone advice provided by palliative care medical specialists from Waikato</li> <li>• Monthly visiting palliative care medical specialist (service from Waikato since Nov 2011)</li> </ul> <p>Day programme:</p> <ul style="list-style-type: none"> <li>• Every Wednesday at hospice facility</li> </ul> <p>Equipment loan:</p> <ul style="list-style-type: none"> <li>• Short and long term loan of equipment to support care at home</li> </ul> <p>Family support:</p> <ul style="list-style-type: none"> <li>• Grief and loss support, bereavement counselling</li> <li>• Carer support</li> </ul> <p>Volunteer support services:</p> <ul style="list-style-type: none"> <li>• Volunteers support fundraising activities and the hospice shops, run the day programme and transport people to/from the day programme if required.</li> </ul> <p>Education:</p> <ul style="list-style-type: none"> <li>• Introduction to palliative care</li> <li>• Topic specific sessions as required e.g. pain and symptom management/bowel obstruction, grief, loss and bereavement</li> </ul> |

|   |   |
|---|---|
|   | <ul style="list-style-type: none"> <li>• Syringe Driver training and competency</li> <li>• LCP education</li> <li>• Fundamentals of Palliative Care (Hospice NZ programme)</li> <li>• Access to Genesis Oncology Trust breakfast lectures</li> <li>• Essentials of Hospice Palliative Care for Volunteers</li> <li>• Advance Care Planning/Funeral Planning</li> </ul>  |
| <b>Workforce</b>                              | <p>Rotorua Hospice has a total paid workforce of 14 FTE as at March 2012. This is comprised of :</p> <ul style="list-style-type: none"> <li>• Management / admin - 3 FTE</li> <li>• Clinical director &amp; registered nurses – 7 FTE</li> <li>• Care assistants – 4 FTE</li> </ul> <p>In addition, the medical specialist monthly visiting service is contracted from Waikato.</p> <p>Volunteers – around 45 volunteers contribute approx 14,000 hours per annum, to support fundraising activities of the hospice (e.g. the hospice shops) and to run the day programme. Volunteers are not used for support in people's homes or for patient transport (other than to/from the day programme).</p> |
| <b>LCP</b>                                    | <p>Rotorua Hospice is lead organisation for implementation of the end of life Liverpool Care Pathway in the Rotorua region.</p> <ul style="list-style-type: none"> <li>• Implemented into 2 pilot sites in 2010 (medical unit of Rotorua Hospital and one residential care facility) supported by funding from the Ministry of Health Service Development Fund.</li> <li>• Additional sites added for implementation in 2011/12 (4 residential care facilities &amp; hospice community team).</li> </ul>  |
| <b>Information/patient management systems</b> | <p>Rotorua Hospice has historically managed patient data using a combination of access database, Excel spreadsheets and a paper based system. Inconsistency of data entry has been identified as an issue.</p> <p>Implemented PalCare (2011/12) as a part of a regional initiative lead by Waipuna Hospice. Went 'live' with PalCare 16 Jan 2012.</p>   |
| <b>Quality standards</b>                      | HealthShare Audit   |
| <b>Key linkages</b>                           | <p>Local and Lakes:</p> <ul style="list-style-type: none"> <li>• General practice teams and PHO teams</li> <li>• Community pharmacies</li> <li>• Rotorua residential care providers</li> <li>• Rotorua hospital services e.g. cancer nurse specialists &amp; Hunga Manaaki</li> <li>• BOP DHB Planning and Funding, physiotherapists, occupational therapists, social work</li> <li>• Māori health providers</li> <li>• Cancer Society and other support groups</li> </ul> <p>Regional/national:</p> <ul style="list-style-type: none"> <li>• Hospices in other DHBs</li> <li>• Midland Palliative Care Work Group</li> <li>• Midland Cancer Network</li> <li>• Hospice New Zealand</li> </ul>        |

## Rotorua Hospice– Patient demographics

|   | 2007     | 2008              | 2009        | 2010        |
|---|----------|-------------------|-------------|-------------|
| <b>Patients</b> (deaths and discharges)         |          |                   |             |             |
| Total Patient numbers                           | 167      | 199               | 174         | 182         |
| Deaths  | 164 98 % | 183 92 %          | 163 94 %    | 175 96 %    |
| Transfers/discharges                            | 3 2 %    | 16 8 %            | 11 6 %      | 7 4 %       |
| Active Patients – avg per month                 |          |                   |             |             |
| <b>Age</b> (deaths and discharges)              |          |                   |             |             |
| Average age (years)                             | 70.9     | 71.6              | 72.1        | 72          |
| < 65yrs   | 44 28 %  | 56 29 %           | 54 32 %     | 52 29 %     |
| 65 yrs and over                                 | 112 72 % | 136 71 %          | 117 68 %    | 125 71 %    |
| <b>Gender</b> (deaths and discharges)           |          |                   |             |             |
| Male  | 98 59 %  | 84 43 %           | 94 54 %     | 109 60 %    |
| Female  | 69 41 %  | 111 57 %          | 80 46 %     | 73 40 %     |
| <b>Ethnicity</b> (deaths and discharges)        |          |                   |             |             |
| European  | 117 70 % | 121 61 %          | 113 65 %    | 122 67 %    |
| Maori   | 44 26 %  | 70 35 %           | 52 30 %     | 55 30 %     |
| Other   | 1 1 %    | 4 2 %             | 7 4 %       | 5 3 %       |
| not reported                                    | 5 3 %    | 4 2 %             | 2 1 %       | 0 0 %       |
| <b>Place of Death</b>                           |          |                   |             |             |
| Home  | 117 71 % | 136 74 %          | 118 72 %    | 124 71 %    |
| Hospital  | 17 10 %  | 19 10 %           | 15 9 %      | 19 11 %     |
| Care Home                                       | 30 18 %  | 28 15 %           | 28 17 %     | 32 18 %     |
| blank   |          |                   | 2 1 %       |             |
| <b>Diagnosis</b> (deaths and discharges)        |          |                   |             |             |
| Cancer  | 128 77 % | 156 78 %          | 130 75 %    | 125 69 %    |
| Non cancer                                      | 38 22 %  | 40 20 %           | 44 25 %     | 57 31 %     |
| unknown   | 1 <1 %   | 3 2 %             |             |             |
| <b>Length of Stay (days)</b>                    |          |                   |             |             |
| Average all patients                            | 103*     | 107**             | 123         | 116         |
| Average LOS cancer diagnosis (537pts)           | 137*     | 153**             | 121         | 129         |
| Average LOS all non cancer (179 pts)            | 42       | 64                | 129         | 90          |
| <b>Number of assessments</b>                    |          |                   |             |             |
| Initial and ongoing assessments - total         |          |                   | 7389        | 8741        |
| Average assessments per patient                 |          | Data not complete | 42.5        | 48          |
| Personal care visits - total                    |          |                   | 4101        | 4087        |
| Average personal care visits per patient        |          |                   | 23.6        | 22.5        |
| Bereavement visits - total                      |          |                   | 238         | 312         |
| Average bereavement visits per death            |          |                   | 1.5         | 1.8         |
| <b>Residential care</b> (respite & end of life) |          |                   |             |             |
| Number of days***                               |          | (07/08) 342       | (08/09) 362 | (09/10) 446 |
| Avg bed days per patient                        |          | 1.6               | 2           | 2.5         |

Source: Ministry of Health monitoring returns as completed by Rotorua Hospice

\* LOS has been adjusted to exclude 1 patient with LOS of 5.4 years

\* LOS has been adjusted to exclude 2 patients with LOS of 5.6 yrs and 10 yrs.

\*\*\* Note this is supplied as financial year

## Services to Improve Access (SIA) funding

Primary health organisations (PHOs) are funded by district health boards to support the provision of essential primary health care services through general practices to those people who are enrolled with the PHO. Within the Lakes DHB area there are two main PHOs:

- Heath Rotorua PHO
- Midlands Health Network

All general practices within Lakes are a part of one of the PHOs above with the exception of the Mangakino GP practice.

Enrolling with the PHO is a personal choice. People who choose not to enrol with a PHO do not have access to fee subsidies and other benefits offered to enrolled people of the PHO.

A key priority for implementation of the Ministry of Health's Primary Health Care Strategy is to reduce barriers for the groups with the greatest need through additional services to improve health and improving access to existing first-contact services. The Ministry of Health has made available Services to Improve Access (SIA) funding for all PHOs to reduce inequalities among those populations that are known to have the worst health status.

SIA funding is not guaranteed on a long term basis and could be reviewed according to priorities.

Health Rotorua and Midlands Health Network currently make SIA funding available to improve the care of terminally ill people as summarised below:

|  | Health Rotorua PHO  | Midlands Health Network (Taupo/Turangi)   |
|--|---|---|
| <b>Eligibility</b>                         | To be registered in the Palliative Care programme the patient must: <ul style="list-style-type: none"> <li>• Be enrolled with Health Rotorua PHO, and</li> <li>• Have a life expectancy of 6 months or less (a 3 month extension may be granted when the patient has been enrolled for more than 6 months and still has funding available), and</li> <li>• Have need of acute symptom control, and/or</li> <li>• Have an acute psychological/spiritual/existential need.</li> </ul> | <ul style="list-style-type: none"> <li>• Must be an enrolled patient</li> <li>• Terminal illness and unable to visit the surgery for consultations</li> <li>• In GPs opinion unlikely to survive beyond 1 year</li> <li>• GP to provide 24hr phone contact for patient &amp; family.</li> </ul>   |
| <b>Exclusions</b>                          |   | <ul style="list-style-type: none"> <li>• Patients who are in a resthome (unless temporarily for respite care)</li> </ul>  |
| <b>Provisions i.e. What can be claimed</b> | <ul style="list-style-type: none"> <li>• Prescription charge</li> <li>• Surgery consults</li> <li>• Home visits by GP</li> <li>• Traditional Māori therapy</li> </ul> <p>Maximum per visit \$75 and maximum per patient \$700</p>   | <ul style="list-style-type: none"> <li>• Referral to Hospice</li> <li>• Telephone consultation</li> <li>• Home visit by GP</li> <li>• Mileage for home visit if distance is in excess of 20km for a round trip</li> </ul> <p>Fees for above range from \$21.50 to \$95. Maximum of 8 home visits per patient (extension can be applied for)</p> |
| <b>Indication of volume</b>                | 1298 claims 2009/10 year.   | 525 claims in 2009/10   |

## APPENDIX 8

### Palliative Care Funding (Includes funding specifically identifiable as palliative care)

| Provider                           |          |   | Contract 2009/10 | Contract 2010/11 | Contract 2011/12 |
|------------------------------------|----------|---|------------------|------------------|------------------|
| <b>TAUPO</b>                       |          |   |                  |                  |                  |
| Lake Taupo Hospice Trust           | COPL0001 | Palliative Assessment & Care Coordination   | 159,581          | 159,581          | 161,975          |
|                                    | COPL0002 | Palliative Clinical Care - additional MOH 'Boost Hospice' funding (fixed term)            | 92,500           | 92,500           | 92,500           |
|                                    | COPL0002 | Palliative Clinical Care - additional MOH 'Access to Care pressures' funding (fixed term) | 39,000           | 39,000           | 39,000           |
|                                    | COPL0004 | Intensive end of life support/ LCP implementation   | 19,597           | 10,000           | 20,000           |
|                                    | COPL0002 | Clinical Care - night staff   |                  | 5,000            | 5,075            |
|                                    |          |   | <b>310,678</b>   | <b>306,081</b>   | <b>318,550</b>   |
|                                    |          |   |                  |                  |                  |
| Lakes DHB District Nursing - Taupo | COPL0002 | Palliative care district nursing visits   | 131,100          | 128,543          | 133,081          |
| Residential care facilities        |          | NASC funding for residential respite - Taupo  | 112,510          | 112,510          | 114,198          |
|                                    |          | <b>Subtotal Taupo</b>   | <b>554,288</b>   | <b>547,134</b>   | <b>565,829</b>   |
| <b>ROTORUA</b>                     |          |   |                  |                  |                  |
| Rotorua Community Hospice Trust    | COPL0001 | Palliative Assessment & Care Coordination   | 206,492          | 206,492          | 209,589          |
|                                    | COPL0002 | Palliative Clinical Care  | 206,492          | 206,492          | 209,589          |
|                                    | COPL0003 | Palliative Clinical Care - additional MOH 'Boost Hospice' funding (fixed term)            | 93,534           | 93,534           | 93,534           |
|                                    | COPL0003 | Palliative Clinical Care - additional MOH 'Access to Care pressures' funding (fixed term) | 56,000           | 56,000           | 56,000           |
|                                    | COPL0004 | Intensive end of life support   | 107,062          | 107,062          | 108,668          |
|                                    | COPL0005 | Intensive end of life support/LCP implementation  |                  |                  | 29,433           |
|                                    |          | <b>Subtotal Rotorua</b>   | <b>669,580</b>   | <b>669,580</b>   | <b>706,813</b>   |
|                                    |          |   |                  |                  |                  |
| Waikato DHB                        |          | 24/7 specialist medical telephone advice service  | 5,630            | 5,727            | 5,813            |
| <b>TOTAL Lakes DHB funding</b>     |          |   | <b>1,229,498</b> | <b>1,222,441</b> | <b>1,278,455</b> |

| PHO Funding  |  |             |                   |
|--|--|-------------|-------------------|
| Midlands Health Network<br>(Taupo/Turangi/Mangakino) |  | SIA funding | 525 claims 09/10  |
| Health Rotorua PHO (Rotorua)                         |  | SIA funding | 1298 claims 09/10 |
| <b>TOTAL PHO funding</b>                             |  |             |                   |

**Notes:**

Rotorua residential respite/end of life care is included in bulk funding for Rotorua Hospice.

**Inter District Flows:**

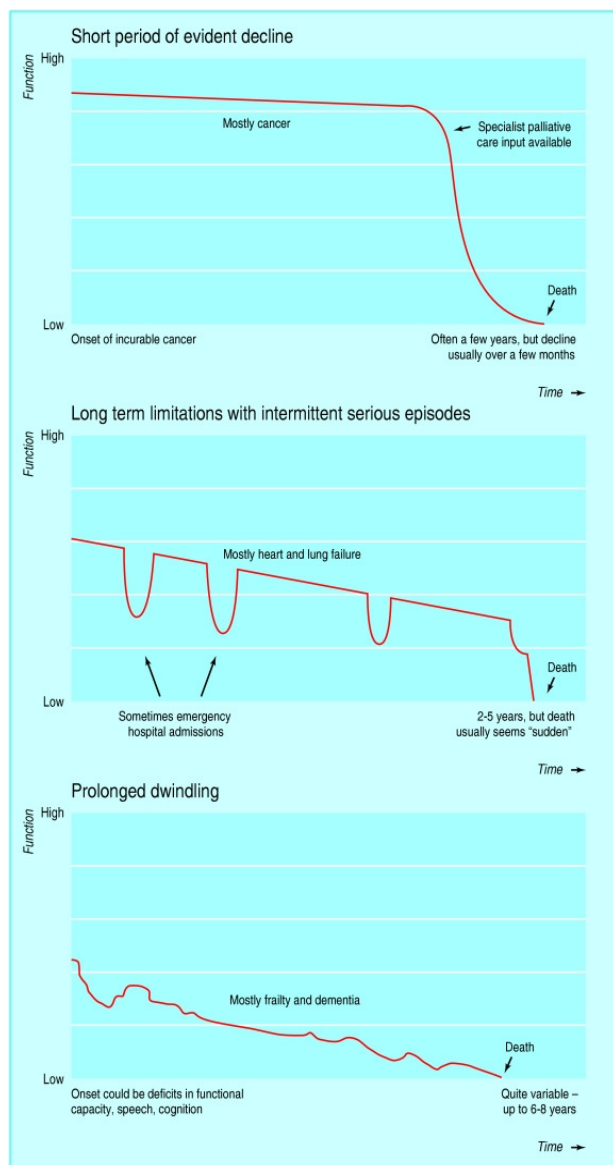
Because the natural flow for people in Murupara / Ruatahuna is towards Rotorua, Rotorua Community Hospice is expected to provide a range of hospice services to people who move into Lakes at the end of life. The cost of any hospice service for people living in the community with their families is absorbed into Rotorua Community Hospice and covered by Lakes DHB. The cost of end of life care in a Rotorua residential care service is covered by an IDF arrangement between Lakes DHB and BOP DHB for a small number of people. Rotorua Community Hospice receives additional funding to recognise this service need.

For Murupara clients who are discharged home from Rotorua Hospital, they are expected to access EBOP hospice services and access to aids and equipment from BOPDHB. There are times when this arrangement is slow to be actioned and Rotorua Community Hospice can be expected to provide cover.



## Illness trajectories and palliative care

Figure 1



**Source:**

**Figure 1.**

Lynn J, Adamson DM. *Living well at the end of life. Adapting health care to serious chronic illness in old age*. Washington: Rand Health, 2003.

**Source article:**

Murray SA, Kendall M, Boyd K, Sheikh A. *Illness trajectories and palliative care*. BMJ April 2005; vol 330, pp 1007-1011.

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC557152/>

**Trajectory 1: short period of evident decline, typically cancer**

This entails a reasonably predictable decline in physical health over a period of weeks, months, or, in some cases, years. This course may be punctuated by the positive or negative effects of palliative oncological treatment. Most weight loss, reduction in performance status, and impaired ability for self care occurs in patients' last few months. With the trend towards earlier diagnosis and greater openness about discussing prognosis, there is generally time to anticipate palliative needs and plan for end of life care. This trajectory enmeshes well with traditional specialist palliative care services, such as hospices and their associated community palliative care programmes, which concentrate on providing comprehensive services in the last weeks or months of life for people with cancer. Resource constraints on hospices and their community teams, plus their association with dying, can limit their availability and acceptability.

**Trajectory 2: long term limitations with intermittent serious episodes**

With conditions such as heart failure and chronic obstructive pulmonary disease, patients are usually ill for many months or years with occasional acute, often severe, exacerbations. Deteriorations are generally associated with admission to hospital and intensive treatment. This clinically intuitive trajectory has sharper dips than are revealed by pooling quantitative data concerning activities of daily living. Each exacerbation may result in death, and although the patient usually survives many such episodes, a gradual deterioration in health and functional status is typical. The timing of death, however, remains uncertain. In one large study, most patients with advanced heart failure died when expected to live for at least a further six months. Many people with end stage heart failure and chronic obstructive pulmonary disease follow this trajectory, but this may not be the case for some other organ system failures.

**Trajectory 3: prolonged dwindling**

People who escape cancer and organ system failure are likely to die at an older age of either brain failure (such as Alzheimer's or other dementia) or generalised frailty of multiple body systems. This third trajectory is of progressive disability from an already low baseline of cognitive or physical functioning. Such patients may lose weight and functional capacity and then succumb to minor physical events or daily social "hassles" that may in themselves seem trivial but, occurring in combination with declining reserves, can prove fatal. This trajectory may be cut short by death after an acute event such as a fractured neck of femur or pneumonia.

### **S.W.O.T. Analysis –Taupo palliative care services** (as at April 2011)

#### **Strengths** (build on)

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##### **Services, facilities and equipment:**

- Single point of entry and care coordination
- Strong primary practice and community support for the model
- Experienced specialist hospice nursing and district nursing staff
- Collaborative model (hospice/district nursing) to reach people in the remote/rural areas
- District nursing cover 24/7
- Visiting palliative care medical specialist clinics, education and home visits when necessary
- 24/7 telephone support from palliative care medical specialist
- Good hospice facility and support infrastructure
- End of life Liverpool Care Pathway implemented in all settings
- Community donated equipment
- Dedicated hospice education role for improved education of generalists and carers
- Grief and loss support in residential care facilities
- Taupo grief and loss service run by local funeral directors
- Four registered nurses in Taupo commenced postgraduate education in palliative care (also see weaknesses – one from residential care sector received CTA funding, three from hospital did not)
- Involved in national developments and initiatives

##### **Strong relationships and networks with:**

- primary practices
- local services e.g. pharmacy, residential care
- local hospital staff – hospice staff attend Taupo Hospital MDT meetings
- Lakes DHB cancer liaison nurses and nurse practitioners in Turangi/Mangakino
- local Māori - Tuwharetoa involved in hospice governance, high level of presence on local marae
- volunteers and community support
- other regional & national specialist palliative care providers

##### **Funding:**

- Community willingness to donate funds
- PHO 'Services to Improve Access' funding available to general practice enrolled people

#### **Weaknesses** (eliminate/manage)

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##### **Access to services**

- GPs increasingly reluctant to do after hours work.
- Lack of health and support services in remote/rural areas
  - out of hours GP (Turangi)
  - short term respite care
- No dedicated palliative care beds or GP beds, difficulty getting a hospital level bed in residential care.
- Model of care does not have allied health as a part of the multidisciplinary team. Access to allied health is via Taupo Hospital - issues with referral wait time and lack of community equipment.
- Access to community social work – no capacity for community referrals to the Taupo DHB social worker unless person is an inpatient.
- People under the age of 65 are often admitted to an aged care facility for respite care. This is not always the most appropriate environment for this group of people.

## **Funding**

- Fragmentation of funding across different services
- DHB funding for specialist services not linked to volumes
- Difficulties experienced with different funding levels for various stages of care if moving from resthome level care to higher level palliative care e.g. person with an acute incident in residential care needing to go to 24/7 care but can't get an assessment for funding (6 week stand down)

## **Awareness of palliative care approach**

- The public are unsure of what palliative care means, the services available within the Taupo region and how to access them
- Not all clinical stream models of care include the development of a palliative care approach and integration along the continuum of care. Late referral practices lead to increased acuity of patients (anecdotal – no acuity measurement tool in use).

## **Forecasted growth**

- Ageing population – increasing proportion of population in 65+ yrs age group, increasing number of deaths
- Increase in the incidence of cancer
- Increased referrals for people with non-malignant diseases due to increased incidence and awareness of other services that recognise the value of palliative care support

## **Workforce**

- Small workforce number - problems with economy of scale and how to address the growing demand.
- Access to funding by individuals to undertake further education & specialisation in palliative care
- Māori representation in the palliative care workforce (this is a nationwide issue)
- Meeting development needs of palliative care workforce in rural areas
- Lack of appropriate clinical supervision for those delivering palliative care
- Availability of visiting medical specialists from Waikato & cover for leave
- Maintenance of standards of palliative care in residential care due to:
  - turnover of RNs in the sector, due to both supply and pay rates
  - use of agency nurses and health care assistants who may lack palliative care knowledge and experience
  - variable symptom management, due to availability/skill of medical support (usually GP)

## **Lack of quality information, standards, specifications and performance indicators**

- Fragmentation of patient information – various systems, lack of integration (GPs/hospice/district nurses/hospital)
- Hospice nurses cannot access patient clinical information from Taupo Hospital (*since addressed*)
- Variable data collection and information reporting
- Poor monitoring and evaluation of contract and services, monitoring is not integrated
- No defined minimal data set and/or performance indicators
- Equip 4 not yet introduced by DHB/NGOs into resthomes

## **Opportunities (exploit)**

- Workforce development and education initiatives under way e.g. Hospice NZ new Fundamentals of Palliative Care education package, education for whānau as carers
- PalCare implementation - improved data collection, availability of patient information and consistency of information
- Midlands Health Network development of Integrated Family Health Centres/Networks - opportunity to improve access to primary practice and care co-ordination between community, primary and secondary/specialist palliative care
- Hospice NZ standards
- Advance Care Planning
- Current service development work by MOH/national groups:
  - Development of a role delineation model for palliative care
  - Development of models of care in palliative care
  - Development of a national funding model

- Specialist Palliative Care service specifications
  - Palliative Care Council Health Needs Analysis work
  - Health Workforce NZ palliative care workforce service review
- Use of LCP for improving end of life care
- Increased regional collaboration of palliative care providers in Midland
- Training and development of generalists, carers and family/whānau, particularly those in rural/remote areas
- Raise community awareness of palliative care and services (e.g directory of services)
- Development of integrated clinical guidelines, standards, referral pathways and tools
- Promotion of palliative care philosophy with primary health teams, residential care, Māori Health providers and specialist health services

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#### **Threats** (ease/lower)

- Increase in volume of people from ageing population – DHB funding not linked to volumes
- Increased quality expectations without infrastructure and resources to develop and support
- Frustration of health professionals due to competing health service demands and limited access to resources to develop palliative care services
- Reducing availability of community funding due to recession
- SIA funding is part of a flexible funding pool therefore it could be removed
- Private provider / new entrant

### **S.W.O.T. Analysis –Rotorua palliative care services**

(as at April 2011)

#### **Strengths (build on)**

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##### **Services, facilities and equipment:**

- Single point of entry and care coordination
- Committed and experienced specialist hospice nursing staff, low turnover
- Hospice palliative care co-ordinator and Team Leader (when required) attend Rotorua Hospital MDT meetings
- Hospice nurse cover available 24/7 accessible 'out of hours'
- Strong primary practice and community support for the model
- Local GP's are very competent in their delivery of palliative care and are able to visit at home or in rest homes as part of their funding and work in very close collaboration with the hospice specialist nurses
- 24/7 telephone support from palliative care medical specialist
- Good hospice facility and support infrastructure
- End of life Liverpool Care Pathway implementation under way
- Hospice nurses oversee care of palliative people in resthomes – maintains quality of care for these people, resthome staff keen to learn/develop
- Community donated equipment with systems and processes in place for access and management
- Grief and loss support in residential care facilities
- Involved in national developments and initiatives
- Accessing CTA funding for nurse development

##### **Strong relationships and networks with:**

- primary practices
- local services e.g. pharmacy, residential care
- local hospital staff – hospice staff attend Rotorua Hospital MDT meetings
- Lakes DHB cancer liaison nurses, medical/nursing, social workers and Hunga Manaaki
- local Māori
- volunteers and community support
- Established networks with other regional & national specialist palliative care providers

##### **Funding:**

- Community willingness to donate funds
- PHO 'Services to Improve Access' funding available to general practice enrolled people

#### **Weaknesses (eliminate/manage)**

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##### **Access to services**

- No formal arrangement for specialist palliative care medical service including clinics, GP and hospital staff education and when necessary home visits
- No dedicated palliative care beds or GP beds
- Model of care does not have allied health as a part of the multidisciplinary team. Access to allied health is via Rotorua Hospital
- People under the age of 65 are admitted to an aged care facility for end-stage care if not able to be managed at home with hospice and family/whanau support. This is not always the most appropriate environment for this group of people.

##### **Funding**

- Fragmentation of funding across different services
- DHB funding for specialist services not linked to volumes

- Funding for care of under 65's - NASC Rotorua will not accept these people because they are under 65 years. Hospice palliative funding is for a maximum of 31 days. Once hospice funding is completed these are reviewed on a case by case basis with Lakes Planning and Funding. Some short-term palliative funding is available through this channel.

### **Awareness of palliative care approach**

- The public are unsure of what palliative care means and services available within the Rotorua region.
- The public can be strongly influenced by medical specialists and very often their focus is on cure resulting in late referral. Late referral practices lead to increased acuity of patients (anecdotal – no acuity measurement tool in use).
- Not all clinical stream models of care include the development of a palliative care approach and integration along the continuum of care.

### **Forecasted growth**

- Ageing population – increasing proportion of population in 65+ yrs age group, increasing number of deaths
- Increase in the incidence of cancer
- Increased referrals for people with non-malignant diseases due to increased incidence and awareness of other services that recognise the value of palliative care support.

### **Workforce**

- Small workforce number - problems with economy of scale and how to address the growing demand.
- Māori representation in the palliative care workforce (this is a nationwide issue)
- Availability of visiting medical specialists from Waikato & cover for leave
- Maintenance of standards of palliative care in residential care due to:
  - turnover of RNs in the sector, due to both supply and pay rates
  - use of agency nurses and health care assistants who may lack palliative care knowledge and experience

### **Lack of quality information, standards, specifications and performance indicators**

- Fragmentation of patient information – various systems, lack of integration (GPs/hospice/district nurses/hospital)
- Hospice nurses cannot access patient clinical information from Rotorua Hospital
- Variable data collection and information reporting
- Poor monitoring and evaluation of contract and services, monitoring is not integrated
- No defined minimal data set and/or performance indicators
- Equip 4 not yet introduced by DHB/NGOs into resthomes

### **Opportunities (exploit)**

- Workforce development and education initiatives under way e.g. Hospice NZ new Fundamentals of Palliative Care education package
- PalCare implementation - improved data collection, availability of patient information and consistency of information
- PHO and Whanau Ora developments - opportunity to improve care co-ordination between community, primary and secondary/specialist palliative care.
- Hospice NZ standards project
- Advance Care Planning
- Current service development work by MOH/national groups:
  - Development of a role delineation model for palliative care
  - Development of models of care in palliative care
  - Development of a national funding model
  - Specialist Palliative Care service specifications Framework
  - Palliative Care Council Health Needs Analysis work
  - Health Workforce NZ palliative care workforce service review
- Use of LCP for improving end of life care

- Increased regional collaboration of palliative care providers in Midland
- Training and development of generalists, carers and family/whānau
- Raise community awareness of palliative care and services (examples directory of services, Hospice website)
- Development of integrated clinical guidelines, standards, referral pathways and tools
- Promotion of palliative care philosophy with primary health teams, residential care, Māori Health providers and specialist health services

### **Threats (ease/lower)**

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- Increase in volume of people from ageing population – DHB funding not linked to volumes
- Increased quality expectations without infrastructure and resources to develop and support
- Frustration of health professionals due to competing health service demands and limited access to resources to develop palliative care services
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