



PALLIATIVE CARE

DSL Review 2006

NGĀ PEEHITANGA TĀNGATA O TE AO HURUHURI
NGĀ WHAKARITENGA MO TE TIKA ME TE ORA MORIMORIMATAWHAI

THE TRIALS PEOPLE FACE IN A CHALLENGING WORLD
CAN BE OVERCOME BY CARING FOR AND LOVING ONE ANOTHER

**WAIKATO DHB PALLIATIVE CARE
DISABILITY SUPPORT LINK REVIEW**

Report prepared by: Judy Fitness & Jan Hewitt
Waikato DHB Development and Support Unit
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Acknowledgements

Acknowledgement and thanks to the many people inside and outside the Waikato District Health Board who have supported and contributed to the process of reviewing the palliative care Disability Support Link model of care. The Waikato has dedicated staff and community groups who are committed to working towards meeting the needs of the Waikato DHB population and the achievement of the New Zealand Cancer Control Action Plan 2005-2010 and the Waikato Palliative Care Strategy Plan 2005-2010.

EXECUTIVE SUMMARY

The Waikato District Health Board (Waikato DHB) Palliative Care Strategy Plan 2005–2010 (Strategy Plan) goal is to ensure that all providers of palliative care work together with the community to ensure that the New Zealand Palliative Care Strategy is implemented in the most optimal way for the Waikato district. This is to ensure that all people with palliative care needs and their family / whānau have access to essential¹ palliative care services, provided in a co-ordinated and culturally appropriate way.

The vision of the New Zealand Palliative Care Strategy (MOH, 2001) is that palliative care services should be provided for most dying people and their families/whānau in their own home, where this is their wish. The vision also assumes that the family/whānau will be active in assisting with care where this is appropriate.

In November 2005 the Waikato District Health Board (Waikato DHB) approved one-off funding for the formal review of the Waikato Disability Support Link (DSL) palliative care support services. At around the same time, the Waikato Palliative Care Operations Network (Operations Network) was established to provide leadership with operational responsibility to oversee service development and provision of care as outlined within the strategic plan. The six-month project (commenced in February 2006) was to review the current DSL palliative care service.

This was in response to the Strategy Plan recommendation:

“4.5 Waikato DHB planning and funding service should review the Disability Support Link (DSL) palliative care administration function for night relief and respite care to rest homes/ continuing care” (p26).

The purpose of this report is to provide details of the project findings and make recommendations for improvement initiatives.

DSL palliative care support services are provided to patients during the last six weeks of life. The support services are:

- Palliative carer support night/day relief (carer support) - two nights per week or the funding equivalent of \$150 to be used as desired by the client to meet the family / whānau need for carer support at other times of the day
- Respite/end of life rest home/continuing care bed (respite care) - for a maximum of six weeks where the patient is deemed to be in the terminal phase.

Palliative carer support and/or respite care funding commenced 1997-8 to meet a ‘gap’ in the services. At the time palliative care funding commenced, it was deemed that DSL was the most appropriate service to manage the funds because they had an invoicing mechanism and already provided a range of support services for disabled people and their families/whānau. At the time no eligibility criteria for accessing palliative care support services were provided to DSL and although some have subsequently been developed (in 1999), they have never been formally recognised.

Historically, DSL palliative care support services funding has been based on previous expenditure rather than need. Expenditure over the last four financial years has averaged \$384.5k annually and it is likely that this will be inadequate in the future with the forecasted

¹ NZ Palliative Care Strategy (2001) defines essential services as: assessment, care co-ordination, clinical care and support care.

increasing numbers of palliative care patients. The 2006-07 budget is \$429,455 fee for service and \$1,634.38 management fee.

Analysis of DSL data for the 2001-06 financial years indicates an average of six referrals per month for palliative carer support and seven referrals per month for respite care. The last three financial years indicate a proportionally higher demand for rest home/continuing care beds for and decreasing demand for palliative carer support.

The key strengths of the current service are:

- DSL knowledge and ability to administer (single point of entry, invoicing mechanism) the palliative support services, including the availability and knowledge of the DSL manager
- DSL has formed relationships with rest home and continuing care organisations and agencies that provide carer support
- Palliative Care Unit provides specialist palliative clinical advice and guidance to DSL and district nursing as required.

The key weaknesses of the current service are:

- Current contract definitions and eligibility criteria for palliative care support services (DSL for six weeks and Hospice for six months) are not congruent with either the:
 - The New Zealand Cancer Control Strategy Action Plan (MOH, 2005) that aligns with the World Health Organisation (WHO, 2002) definition that “the provision of palliative care is applicable at any stage after diagnosis of a life-threatening illness, and not at the very end of life (terminal phase)” or the
 - New Zealand Palliative Care Strategy (2001) recommendation that palliative care should generally be available to people whose death from progressive disease is likely within 12 months
- Current eligibility criteria for accessing palliative support services are not formalised, creating uncertainty for referrers
- Inequity of services – DSL patients not registered with Hospice Waikato can only access support services through DSL. Hospice Waikato patients are able to access palliative support services through Hospice (non-DHB contracted) and DSL Waikato DHB contracted services
- Service specifications are out of date and not reflecting the services provided
- Access to services, particularly palliative carer support night/day relief is not equitable across the Waikato DHB district due to variable availability of carers
- Waikato DHB contracts for the administration function only for palliative care carer support night/day relief. Inconsistencies with provision of palliative care carer support night/day relief i.e. DSL approves the funds but does not provide the personnel (although will advise) whereas Hospice Waikato will organise the carer
- Funding level does not always meet the full cost of carer support. There are known issues with palliative patients with complex, high cost needs
- Data collection is incomplete with minimal monitoring services

- Nationally it is known there is fragmentation, gaps and issues related to the boundaries of personal health and disability support services and the needs of people with long-term, chronic illnesses

A number of options have been identified within this document. The options in the report discussed are:

1. DSL continues to manage palliative care support services (i.e. approval of services and administration of funds)
2. DSL continues to administer funds with approval given by palliative care co-ordinator
3. PCU manages palliative care support services
4. Hospice Waikato manages palliative care support services
5. Acute Home Care Support Services expands to manage palliative care support services
6. A 'one stop shop' service co-ordination concept that integrates personal health (palliative care support services and acute home care support services and Disability Support Services (DSS) run through DSL

While outside the scope of the project consideration should be given as progress is made in relation to the:

- Waikato DHB service and campus redevelopment ambulatory Referral Co-ordination Centre. Should the Referral Co-ordination Centre concept be expanded to include support services?
- National boundary issues between personal health and disability support services for people with chronic medical illnesses
- Longer term options related to addressing the issues related to patients who want to remain / die in their home accessing regulated and / or non-regulated carers within the community
- Review of national palliative care services specifications.

Option six was considered to be the preferred longer-term option for the Waikato DHB, but this option is outside the scope of the project and would require further analysis. The option would combine all support services which are available to a palliative care patient and their family/whānau based on need, thus providing a more timely and seamless provision of service, reducing duplication of administration and creating a single point of entry for referrers. It is recognised that this option requires a long-term approach since it will necessitate the review of current contracts, funding and service provision arrangements and development of a change management plan.

The recommended option is option one where DSL remains the lead provider that manages and administers the palliative care support services contract for the Waikato DHB. Improvements to the current systems and processes will be implemented to enhance the quality of the services. The following recommendations can occur with a small additional investment.

The quality improvements will include:

- The proposed eligibility criteria, assessment and referral tool and guidelines are approved and implemented. Training and information is provided to referrers on the new tools and guidelines. These tools / guidelines will reduce the need for DSL to refer back to the referred and / or make contact with PCU for advice
- DSL utilise increased contracted funds to employ a 0.5 fte for administration of the service co-ordination. Funding would come from the sustainable funding increase of 2006-07
- PCU continue to provide DSL clinical support and guidance
- Improved data collection through the development of a minimal data set
- Waikato DHB planning and funding clarify with DSL contractual reporting and monitoring requirements in relation to palliative care support services
- DSL explore the option of referrals routed through the Referral Co-ordination Centre.

A longer-term recommendation to increase access to palliative care support services firstly to meet the timeframes of:

- The New Zealand Palliative Care Strategy (2001) of twelve months and
- The New Zealand Cancer Control Action Plan (2005) timeframe of any stage after diagnosis of a life-threatening illness

will require significant investment. Additional funding would need to go through the Waikato DHB prioritisation process and be phased in over a 5 – 10 years.

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INTRODUCTION

The Waikato Palliative Care Strategy Plan 2005-2010 (Hewitt, 2005) provides direction for an integrated and co-ordinated palliative care service. The aim is that all people with palliative care needs and their family / whānau are offered timely access to quality palliative care services throughout the Waikato district.

In November 2005 the Waikato District Health Board (Waikato DHB) approved one-off funding for the formal review of the Waikato Disability Support Link (DSL) palliative care support services. At around the same time, the Waikato Palliative Care Operations Network (Operations Network) was established to provide leadership with operational responsibility to oversee service development and provision of care as outlined within the strategic plan. The six-month project (commenced in February 2006) was to review the current DSL palliative care service (refer appendix 1 project proposal).

The purpose of this report is to provide details of the project findings and make recommendations to the Operations Network on improvement initiatives for Waikato DSL palliative care support services.

The goal of the review is to ensure that patients in the Waikato DHB have improved access and equity of palliative care support services.

Definitions

The Waikato DHB Palliative Care Strategy Plan 2005-2010 (Hewitt, 2005) defines palliative care as:

“...an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual” (World Health Organisation, 2002; Ministry of Health, 2005).

A fundamental shift has been the recognition that the provision of palliative care is applicable at any stage after diagnosis of a life-threatening illness, and not at the very end of life (terminal phase)” (p.13).

The palliative care support services that DSL administer are:

- Funding approval by DSL for Palliative Care Carer Support Night/Day Relief (carer support) consists of carer support for two nights per week or the funding equivalent of \$150 to be used as desired by the client to meet the family’s needs for carer support at other times of the day.
- Funding approval by DSL for Respite/‘End of Life’ Bed (respite care) at a Rest Home/Continuing Care (RH/CC) facility is for a maximum of six weeks where the patient is deemed to be in the terminal phase.

Methodology

The project objectives were to:

- Identify current level of night relief and respite care to resthomes services for recognised Waikato DHB palliative care patients. Identify all service providers. Complete SWOT analysis of current service. Identify any inequities of access
- To identify the workload required to support service co-ordination for night relief and respite care
- Identify if the current funding level is adequate and identify appropriate organisation to administer funds
- To review other models nationally.
- To develop access criteria and guidelines to access the two service components
- To develop standards, key performance indicators and a data set for reporting and monitoring
- To recommend the model and plan for the future. The plan will include implications for resources, contracts, financials, timelines and performance measures.

The following project approaches were taken:

- Establishment of a project steering group with support of a project officer for six months 1 January – 30 June 2006 (project officer was only available for four months) (refer project proposal, appendix 1)
- Identification and review of the current palliative care support providers and services within the Waikato DHB
- A review of the current DSL processes and guidelines (appendix 2)
- Analysis of current data to determine volumes, patterns and trends (appendix 3)
- Key stakeholders were interviewed to establish/confirm current information regarding access to carer support and respite care and to identify any issues with the current system through the development of a Strength, Weaknesses, Opportunities Threats (SWOT) analysis of current DSL palliative care support service (appendix 4)
- Health Equity Assessment Tool (appendix)
- Feedback was sought from community service providers and AGEWISE meeting regarding access to palliative care support services (appendix)
- Stocktake of palliative care support service provision by other New Zealand DHBs (appendix 5)

The structure of the report firstly provides an overview of the current providers in relation to palliative care support services and an analysis of the strengths and weaknesses of the current services. The next section considers the various scenario options for the future and based on the analysis makes recommendations and details an implementation plan.

BACKGROUND

In the year before the death of a cancer patient, the estimated prevalence of anxiety and depression common among informal carers are high – reported to be 46% for anxiety and 39% for depression (Ramirez et al, 1998). Carers' anxiety is rated alongside patients' symptoms as the most severe problem by both patients and families/whānau. Sources of support to enable informal carers to look after dying patients at home include night relief, respite care and domestic services.

The Waikato Palliative Care Strategy Plan 2005–2010 (Hewitt, 2005) was developed, through a process of consultation, review and needs assessment, to provide integrated and co-ordinated Waikato DHB palliative care service. Underpinning the strategy vision is a community-based model of palliative care services. The plan includes the recommendation for:

“4.5 Waikato DHB planning and funding service should review the Disability Support Link (DSL) palliative care administration function for night relief and respite care to rest homes/continuing care” (Hewitt, 2005. p26).

In the Waikato DHB, funding for palliative care carer support and respite care is primarily accessed through DSL. However, Hospice Waikato provides a package of home based palliative care services for Hamilton, Cambridge and Ngaruawahia which includes carer support and has four community inpatient beds based in Hamilton for short-term respite care.

The background section of palliative care providers in relation to support services indicates the complexity and links. The providers discussed include DSL (Older Persons and Rehabilitation Service), Hospice Waikato, Hospice Tokoroa, Palliative Care Unit (PCU) (Oncology Services) and Acute Home Support (Rural Hospitals and Community Based Services).

Disability Support Link (DSL)

Palliative care respite funding commenced 1997-8 to meet a gap in services. At the time palliative care funding commenced, it was deemed that DSL was the most appropriate service to manage the personal health palliative care funds because they had an invoicing mechanism and already provided a range of support services for disabled people and their families/whānau.

On commencement DSL was not given any eligibility criteria for establishing the palliative care support service. In 1999, the manager of DSL and the Waikato Hospital Regional Co-ordinator (PCU) jointly developed simple criteria for eligibility. Despite several attempts these were never formally recognised by the Regional Health Authority; however, they have remained the DSL guidelines (appendix 2) for determining eligibility to palliative care support services funding.

These guidelines state “palliative care is a term used to define the care that is offered to patients with active, progressive, advanced disease which is unresponsive to curative treatment”.

DSL approved palliative care funding only when the patient was deemed in the terminal phase (i.e. likely to die within the next six weeks).

In approximately 2002, the manager of DSL was instructed to contain spending to previous levels (approximately \$350k) awaiting devolution of the funds from the Ministry of Health to the Waikato DHB (which occurred October 2003). Funding for palliative care was not

explicit and DSL discretionary funding mechanism was used for invoicing requests that did not meet other funding criteria.

Since commencement of the project the Waikato DHB Planning and Funding have contracted for the personal health palliative care support service explicitly. The 2006/07 Draft Needs Assessment and Service Co-ordination (NASC) Service Level Agreement, does include palliative care funding –

- HOP2004 D Palliative Care fee for service (capped at \$429,455) and
- COOC044 new palliative management funding (\$1,634.28).

2005-06 palliative support services contract budget was \$399,264 fee for service and \$1,587.72 management funding.

The palliative management funding is a new contractual component to allow DSL to allocate dedicated resources to administer the fee for service. However the formula is based on historical funding allocations. DSL have previously requested a management fee for management of this contract, which is outside the scope of Disability Support Services (DSS) contracts.

The 2006-07 NASC agreement provider specific terms and conditions states: service co-ordination for non-HOP clients. While NASC services will include service co-ordination, as previously provided, for the non-HOP services listed below, the DHB will work with the NASC to clarify actual expenditure and service activity against reported service delivery – people referred by the palliative care team.”

Nationally it is recognised that there are boundary issues between personal health and disability support services. The current funding silos for Chronic Medical Illness, Disability Support Services, Acute Home Support and Palliative Care has created boundary disputes and gaps in service for people with disabling chronic long-term conditions.

A draft paper was developed to guide the Ministry of Health and DHBs and proposes that clear, simple processes must be agreed and implemented nationally. It suggests that DHBs will address clinical needs and Disability Support Directorate (DSD) will address long-term disability support needs and that in essence this will mean that people over 65 years will have services funded by the DHBs and under 65 years of age will have services funded by DSS. DHB representatives met (May 2006) to discuss access to support services for people with disabling long-term conditions².

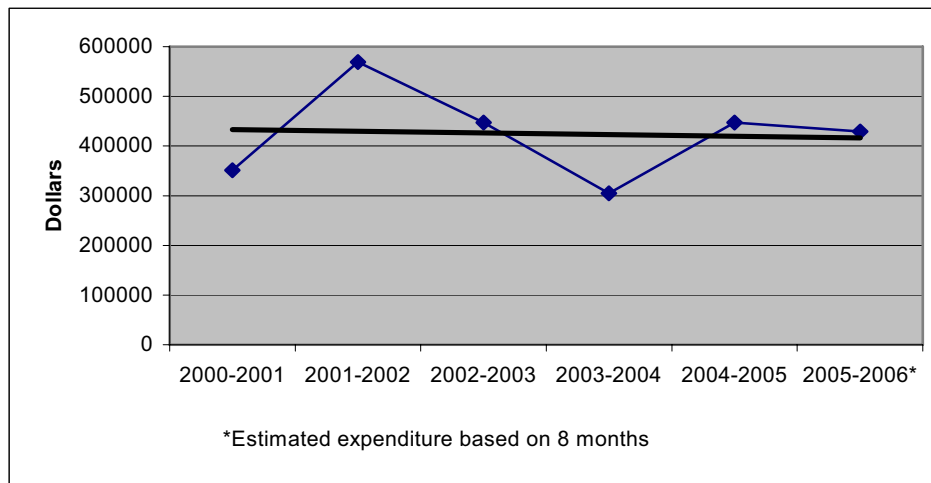
“The DHBs expressed strong concerns that the current funding silos were neither unanimously agreed nor reasonable, and had created significant areas of boundary dispute, and gaps where funding had never been provided for some services. The paper proposes principles and objectives to guide achievement of consistency approaches to the planning and funding of services for people with disabling chronic/long term conditions by the Ministry and DHBs. The principles are fundamental to this process and must be agreed prior to advancing the objectives of the process around addressing gaps in defined need for people with disabling chronic/long term conditions” (DHBNZ, 2006. p1). While outside the scope of this project consideration should be given to developments at a national level.

² This meeting was in response to the Ministry of Health’s document “Funding and Provision of Long Term Support Services for People with Chronic Illness” 9 May 2006 and the DHB devolution processes 2001 & 2003.

DSL Palliative Support Services Funding

An analysis of palliative care budgeted costs approved by DSL in the last 5 financial years show annual fluctuations from \$569k (2001/02) to \$304k (2003-04), an average \$384.5k/year – Chart 1. DSL has continued to approve palliative care support service funding based on the 1999 guidelines.

Chart 1: Invoiced Palliative Care Services 2000 – 2006



Data source DSL

DSL Processes

DSL has procedures to guide staff with the processing of referrals for palliative care support services - these were developed pre-1999 and have not been updated since. Advice may be sought from the PCU Regional Co-ordinator to clarify appropriateness of the referral. Referrals to DSL for palliative care come from:

- Waikato DHB hospitals, including PCU
- District Nurses
- General Practitioners
- Hospice Waikato

The process for palliative care support approved by DSL are either:

- Palliative carer support night/day relief which consists of carer support for two nights per week or the funding equivalent of \$150 to be used as desired by the client to meet the family's needs for carer support at other times of the day (use of these funds is not monitored). Carer support night/day relief is usually granted for a maximum of six weeks. Because younger people tend to remain at home, extra night relief may be provided on advice from District Nurses (DNs) or Hospice Waikato.

DSL does not arrange the carer but can advise families on how to access one. Carer support night/day relief payment can not be paid to someone living at the same address and does not include requests for night relief for other children in the family when parents are accompanying child to Starship for oncology treatment.

- Respite/End of Life bed at a RH/CC facility for a maximum of six weeks (but generally for less). These beds are not currently monitored except where there is uncertainty over discharge prospects. In these circumstances, the manager DSL will ring the RH/CC manager three to four weeks after approval to request an update. If the patient is in the terminal phase, palliative care funding may be continued (based on clinical advice) but if discharge is not a likely option and the patient is not terminal, a Support Needs Assessment is required for Disability Support Services (if elderly) funding. Switching from palliative care support to Disability Support Services can create difficulties with the patient/family because palliative care is free but Disability Support Services necessitates 'means testing'. Approval for respite/'end of life' bed must be obtained from DSL in advance.

If the patient is already in a RH/CC facility, it is possible (but uncommon) to get a 'top up' palliative care respite care funding (paid to the RH/CC) to assist with the extra financial requirements incurred when the patient:

- has been diagnosed with a palliative care condition,
- is end-stage and
- needs higher level of care i.e. moving from RH care to hospital-level care.

The estimated DSL service co-ordination resource is 0.3 - 0.5 fte. As previously indicated there is no dedicated resource that is allocated for service co-ordination function.

DSL Data Analysis

In 2000, DSL established an access database in preparation for a review of palliative care support services funding mechanisms and processes. Information loaded into the database depends on the completeness of the information supplied to DSL but optimally includes name of patient, NHI number, address, name of referrer, date of birth, caregiver/next of kin, care provided, and provider. Date of death, obtained from either the Ministry of Health's monthly advice re deceased patients or faxes from RH/CC facilities or DNs, is added later to ensure payment does not continue after the demise of the patient. Incomplete data and inconsistent identification of the referrer's designation or provider made data analysis difficult.

Volumes per referral type (appendix 3) received by during 2001–06 financial years indicated 440 (48%) referrals for this time period were for RH / CC respite/end of life beds and 381 (41%) were for palliative care carer support night/day relief. Analysis of the data for the 2001 – 2006 financial years indicates an average of six referrals per month for palliative carer support and seven referrals per month for respite/end of life care.

The last three years have shown an increasing use of RH/CC respite/end of life beds and decreasing use of carer support night/day relief whereas in the 2001-02 and 2002-03 years their use each was equal.

Referral requests from Waikato Hospice to DSL have increased in the last two financial years (palliative care carer support night/day relief requests more than doubled in 2005-06 – refer appendix 3).

NHI numbers for patients who had received palliative care support services from 2001-02 – 2004-05 financial years were cross-referenced to data from Waikato DHB Costpro system to

obtain demographic information on age, ethnicity, domicile Territorial Local Authority (TLA) and deprivation index. 29 (4%) of patients could not be cross-referenced. In brief:

- As expected Hamilton was the TLA with the biggest volume (155) of referrals with Thames-Coromandel, Matamata-Piako, Waipa, and Waikato TLAs having the next largest volumes (each being approximately two-thirds of Hamilton's);
- NZ Europeans (79%) were the biggest users of the service followed by 'other Europeans' (11%) and Māori (7%);
- 71–90 year olds were the largest users of the service (76%); and
- More clients living in areas with deprivation rate index scores of six to nine received palliative care support services than those living in areas with lower deprivation rate index scores.

In summary the strength's of the current service is DSL knowledge and ability to administer (single point of entry, invoicing mechanism), relationships with RH/CC and agencies that provide carer support and knowledge of services and providers within the community.

Key weaknesses of the current DSL palliative care support services are that:

- Palliative support services do not align with the WHO and national strategy. Considering that the incidence rate for people with chronic and cancer illnesses is increasing, and that DSL approval processes are only for patients in the terminal phase (three – six weeks), the current levels of funding would be inadequate to allow allocation of palliative care support services by DSL to meet the WHO and NZ Cancer Control Strategy definition of “the applicability of palliative care services at any stage after the diagnosis of a life-threatening illness”.
- There are national and local funding boundaries and definitions issues between personal health and disability support services
- Family and / or DNs have responsibility to find a support person for carer support. The Waikato DHB does not fund service co-ordination for carer support
- Access to qualified and / or non-regulated carer support is often difficult. Funding level is a contribution only, with the family to meet funding shortfall if applicable
- Referrers are sometimes confused regarding eligibility criteria and processes. No formal assessment and monitoring
- DSL do not have dedicated service co-ordination resource
- Data collection incomplete, with minimal monitoring of services.

Waikato Community Hospice Trust

Hospice Waikato provides a package of home based palliative care services (including support services) for people in the last six months of life (children from diagnosis) living in Hamilton, Cambridge and Ngaruawahia. Night relief for three nights may be included as part of the package, however according to Hospice Waikato funding comes from the general budget rather than being specified in the service contract specifications.

Hospice utilises external agency staff e.g. Holistic Healthcare staff, to provide the service.

Hospice Waikato contribute to the palliative collaborative care model for rural Waikato (refer to Collaborative Care review). There is a Memorandum of Understanding (MOU) between Hospice Waikato and Community Health³ that outlines working relationships between the two organisations. Since commencement of the project review of the MOU is in progress.

The Hospice has four community inpatient beds based at Eventhorpe⁴ with bed utilisation for a 10 – 14 day period. Currently, these beds are limited to respite care (up to 14 days) because Hospice Waikato can not provide medical cover to support symptom control. The operational budget for these beds is set, regardless of occupancy.

Hospice Waikato and PCU are jointly recruiting a third palliative care physician to expand community hospice inpatient services to include symptom control.

Data from Hospice Waikato indicate that palliative care carer support (night relief) costs per financial year are decreasing - refer table 1:

Table One - Hospice Night Relief Expenditure	
Financial Year	Expenditure
2002/03	\$16,788.74
2003/04	\$10,259.67
2004/05	\$10,870.36
2005/ 06	*\$6291.19

Data supplied by Waikato Community Hospice Trust

* Projected costs based on July 05 – Feb 06 expenditure data of \$4194.13

However, Hospice Waikato refers to DSL if the patient / family / whānau requires more than the three night's carer support or requires respite care for longer than the 14 days that Hospice Waikato provides. However Hospice is flexible to meet individual / family needs.

Hospice Waikato current service specifications include the provision of night or day carer relief. Waikato Community Hospice Trust service specification (COPL0002 Palliative Clinical Care) is a standard Ministry of Health contract, signed August 2001, which includes:

- COPL002 Clinical Care,
- COPL0002.1 Domiciliary Care,
- COPL0002.2 Inpatient Care
- COPL0002.3 Night or Day Carer Relief
- COPL0002.4 Bereavement Counselling and Support

³ Community Services and Hospice Waikato jointly signed a Memorandum of Understanding (MOU) in 1996. The MOU outlines the relationship between the two organisations. The MOU does not include monetary consideration and was established prior to the formation of DHBs. The MOU states the term will be for no fixed duration but that either party can give 3 months notice of termination of the agreement.

⁴ Eventhorpe Rest Home and Hospital is a 88 to 90-bedded facility, of which 30 are Rest Home beds. Eventhorpe has contracts for convalescent care, transitional care and rehabilitation as well as the four "Hospice" respite beds. Eventhorpe provides nursing care, linen, equipment e.g. pumps, medications, medical care (GP), and supplies. Hospice Waikato nurses visit to maintain their relationship with the client but do not provide any care although may participate in discharge planning.

In July 2004 a joint project between the Ministry of Health, DHBNZ and Hospice NZ investigated the funding of hospices by DHBs (MOH et al, 2005). There were a significant number of findings in particular: “b. Hospices are providing the first two essential services; assessment and co-ordination, and clinical care in line with the NZ Palliative Care Strategy. c. Some hospices are providing the third essential service, support care, under contract and others are providing it without contracts with DHBs” (MOH et al, 2005. p3). There are a number of recommendations for the future that include:

“b. that DHBs and palliative care providers will work together to determine the processes for managing referrals of terminally ill patients.

d. that some hospices are providing elements of the third essential service (support care) from funding outside Vote Health.

e. that DHBs have been directed and have agreed via the Service Coverage Schedule of their Funding Agreements to include essential palliative care services in their services coverage

h. that the planned review of service specifications for palliative care services will proceed in tandem with the review of the Service Level Model” (MOH et al, 2005. p5).

The Waikato DHB Palliative Care Strategy Plan (2005) recognises there are significant issues with the current service specifications. There is a national working party developing national palliative care service specifications.

In summary current weaknesses (appendix 4) with the support services in relation to Hospice Waikato are:

- The growth in referrals from Hospice Waikato to DSL is due to increased demand and patient and family / whānau need
- It is Hospice Waikato’s perception that Waikato DHB do not contract support services (night or day carer relief) from Hospice Waikato. Waikato DHB planning and funding need to clarify contractual components with Hospice Waikato in relation to support care such as night relief
- Service specifications need review (in progress at a national level).

Tokoroa and District Community Hospice

The Tokoroa and District Community Hospice has 12 volunteers and very occasionally will provide night relief (unpaid volunteer) if the family is in dire straits. This service is not advertised because they cannot provide the service on a regular basis due to lack of resources e.g. suitable carers and funding but there is a real need for carer support at night. Tokoroa Hospice predominately provides equipment and support to palliative care families in the Tokoroa community e.g. helping with shopping or sitting with the patient to relieve the carer.

Tokoroa and District Community Hospice service specification (evergreen contract) (COP0002 Palliative Clinical Care) is a standard Ministry of Health contract, signed August 2001, which does not accurately reflect the level of service provided as it includes Domiciliary Care (0002.1), Inpatient Care (0002.2), Night and Day Carer Relief (0002.3), and Bereavement Counselling (0002.4).

Tokoroa Hospice does not provide clinical care although it does provide equipment to clients in Tokoroa. Waikato DHB does not fund volunteer services under the service specifications.

Waikato DHB planning and funding need to update service specifications to reflect what current services are being provided.

Palliative Care Unit (PCU)

PCU is a secondary/tertiary service, staffed by two palliative care physicians (awaiting a third physician) and four specialist palliative care nursing staff. PCU has access to beds in Ward 25 (these are not designated beds, but are accessed on a 'needs' basis and are dependent on availability). The beds should be used for symptom-control only but are occasionally used for respite because of difficulty accessing respite beds in the community. A specialist palliative care consultative service is provided to Waikato and District Hospitals including outpatient/outreach clinics.

PCU assists DSL on patient eligibility criteria as required.

Acute Home Support

Acute Home Support (Rural Hospitals and Community Based Services) is a community-based service. Acute Home Support provides services (for a maximum of six months) that sustain activities necessary for daily living and/or domestic activities for people experiencing difficulty caring for them due to acute illness/medical condition or as a result of hospitalisation for an acute episode.

Private providers are subcontracted to provide the care/services, which are performed by unregulated caregivers. Services such as personal care and/or housework are available from the Acute Home Support service, and can range from as little as one - three hours per week to a maximum of one hour twice a day. Access criteria is based on 2003 Direction of Ministry of Health related to Eligibility for Publicly Funded Personal Health and Disability Services in NZ.

Clients accessing Acute Home Support services include palliative care clients. Carer support and/or respite care is not part of acute home support services.

Acute Home Care Support data shows palliative care client volumes are increasing. Difficulties arise when palliative care patients require services after six months.

Summary of the Current Waikato DHB Model

In the current model, DSL receives referral applications for palliative care support services from GPs, Waikato DHB staff, (including PCU, DNs and hospitals) and Hospice Waikato. Based on the information provided with the referral application, the DSL manager determines eligibility for support services i.e. carer support or respite care. If insufficient information is supplied, the DSL Manager contacts PCU to seek clinical advice.

Approval for respite care is communicated to the RH / CC facility by fax and by letter to the patient / family for carer support. DSL does not initiate any contact with carers but will advise as requested by families or DNs on possible sources.

Feedback from stakeholders (appendix 6) and Health Equity Assessment Tool (appendix 5) was incorporated in the SWOT analysis (appendix 4). Key themes from the analysis identify strengths of the current model are:

- DSL knowledge and ability to administer (single point of entry, invoicing mechanism) the palliative support services, including the availability of the DSL manager

- DSL has formed relationships with rest home and continuing care organisations and agencies that provide carer support
- Palliative Care Unit provides specialist palliative clinical advice and guidance to DSL and district nursing as required
- PCU provides clinical support and guidance to DSL and DNs
- High deprivation areas of the population are accessing support services at a greater proportion compared to low deprivation areas.

Weaknesses in the current model include:

- Current definitions and eligibility criteria for palliative care support services (DSL for six weeks and Hospice for six months) are not congruent with either the:
 - The New Zealand Cancer Control Strategy Action Plan (MOH, 2005) that aligns with the World Health Organisation (WHO, 2002) definition that “the provision of palliative care is applicable at any stage after diagnosis of a life-threatening illness, and not at the very end of life (terminal phase)” or the
 - New Zealand Palliative Care Strategy (2001) recommendation that palliative care should generally be available to people whose death from progressive disease is likely within 12 months
- Current eligibility criteria for accessing palliative support services are not formalised, creating uncertainty for referrers
- Inequity of services – DSL patients not registered with Hospice Waikato can only access support services through DSL. Hospice Waikato patients are able to access palliative support services through contracted services at both Hospice and DSL. Service specifications are out of date and not reflecting the services provided
- Access to services, particularly palliative carer support night/day relief is not equitable across the Waikato DHB district due to variable availability of carers
- Inconsistencies with provision of palliative care carer support night/day relief i.e. DSL approves the funds but does not provide the personnel (although will advise) whereas Hospice Waikato will organise the carer
- Data collection is incomplete with minimal monitoring services
- Nationally it is known there is fragmentation, gaps and issues related to the boundaries of personal health and disability support services and the needs of people with long-term, chronic illnesses
- Predicted palliative care growth requiring community based support strategies and resources to enable people to remain in their homes
- Service specifications out of date and not reflecting the services provided
- Uncertainty whether Hospice Waikato is contracted to provide the third essential palliative care component support care or not
- Unsustainable reliance on DSL manager for 7-day per week access to provide management / decision making function for the service. DSL have viewed palliative care support services as an ‘add-on’ that requires a management fee to resource the work involved.

Other New Zealand DHB Palliative Care Support Service Models

Other NZ DHBs were contacted for information on what palliative care support services they provided (as related to this review), the mechanism for funding and who managed the funds (appendix 5). There was variability in the detail of information obtained from the various DHBs. There is no standardised approach nationally, and this was confirmed a NZ DHB meeting (DHBNZ, 2006).

In essence, nationally there were three different approaches for managing palliative care support services:

1. The DHB contracts with the local hospice to provide palliative care support services. In this situation often the hospice provides all palliative care, both inpatient and community.
2. The local hospice and the district nursing service provide palliative care services. Assessment for palliative care support services is undertaken by a health professional e.g. member of the palliative care team, palliative care co-ordinator, or Hospice. Often funds are split and managed by either the NASC agency or as part of the Hospice contract.
3. Palliative care is provided as a component of another existing contract/service, refer to appendix 5 for examples at Canterbury and Waitemata DHBs. A package is developed based on needs and may include carer support or respite care. As demonstrated with Canterbury DHB significant investment in 2005-06 allowed implementation of this model.

The stocktake of other NZ DHBs was helpful in understanding that most DHBs were having difficulty developing palliative support strategies for the future. Each DHBs palliative model of care was unique.

FUTURE OPTIONS

Options were identified for moving forward. The criteria for developing the options was to:

- Align palliative care support services with the Waikato DHB Palliative Care Strategy to meet the needs of patients and family / whānau
- Build on what we currently have
- Identify the most appropriate provider to manage the palliative care support services
- Where possible address the issues / weaknesses of the current service.

Considerations Outside the Scope of the Project

It should be noted that future investment is required to address, equity and predicted demand for palliative support services and ensure alignment with the NZ Cancer Control Strategy (MOH, 2005). The project was unable to determine the future level of investment.

Developments at a national level to resolve boundary issues between personal health and DSD should be considered with any future developments at a local level.

Development of service specifications and national review of NZ Hospice service level model is outside the scope of this project. A national working group is reviewing and developing national service specification.

The service and campus redevelopment ambulatory model of care is in the implementation phase. A Waikato DHB strategy is for elective referrals to be processed through a single

point of entry. Health Waikato is in the process of developing the Referral Co-ordination Centre. While DSL does have a single point of entry for referrals, consideration should be given to the value of utilising this service for community based palliative care support services referrals.

Discussion on the Options

Potentially, six options have been identified for the approval and administration of palliative care support services and have been summarised in table three. The table considers components in relation to management of a palliative care support service. The advantages and disadvantages for several of the options are similar and the benefits of any proposed change maybe minimal.

It is noted that Waikato DHB has increased the palliative care support services budget for 2006-07 by \$30,237.56 to improve access and recognise resource requirements to manage this service.

The options considered are:

Option One

Option one is to continue with the status quo in addition to the implementation of quality system / process improvements. In this option DSL continues to administer the palliative care support services funds. As previously indicated the financial increase for 2006-07 is \$30,237.56 to improve access and recognise resource requirements to manage this service. A contribution of these funds should support the sustainable funding of an administrator.

The advantages of adopting this option are DSL already have:

- Expertise in invoicing
- Knowledge, expertise and established relationships with community organisations that provide carer support and respite/end of life care
- Allows for employment of dedicated supporting resource without a decline in volumes
- An established database for capturing required information that can be enhanced for monitoring and planning of services
- PCU continue to provide a specialist palliative care co-ordination function to approve eligibility when there is an area of concern
- Quality improvements include revised eligibility criteria, development of palliative care referral assessment form and service allocation guidelines to support the process. These tools and documents have been developed (refer appendix 6) to assist referrers and the process. Improvements to the capture and reporting of data would be required
- It is predicted that the combination of the management fee and the referral / assessment form and guidelines will reduce the DSL manager's workload and provide transparency of access and utilisation.

Disadvantages of this options are:

- Does not address the issue that families / whānau and / or DNs to need to find carers
- Does not address the issues related to regulated and non-regulated carers in the community

- While previous years there have been no increase in funding, by using this years increased budget for administration resources there maybe reduced access for patients and families / whānau
- Continued fragmentation of services and providers in relation to support services to maintain people in the community.

Option Two

Option two considers specialist palliative care providers have a clinical care co-ordination function (refer collaborative care review project) that includes guidance to DSL in managing palliative care support services. It was agreed that this option is a function of providing community based palliative care support services, rather than the other options that explore structure and / or quality improvements. It is proposed that PCU continue to provide a specialist palliative care co-ordination function to approve eligibility when there is an area of concern.

Option Three

Option three considers PCU managing the service. This option was not recommended due to:

- Community based support services are not a core service component of a specialist secondary palliative care service
- PCU does not have an invoicing mechanism or resource to support transferring the service from DSL
- This option does not align with the strategy vision of community based model of palliative care services.

PCU do provide a clinical care co-ordination function to DSL and this function should continue. PCU co-ordinate specialist palliative care, except for patients under the care of Hospice Waikato in Hamilton, Cambridge and Ngauruawhia.

Option Four

Option four considers Hospice Waikato managing the service. This option was not recommended in the first instance, but could be reconsidered in the future. Reasons for not considering this option are:

- Hospice Waikato service coverage currently does not include the whole of the Waikato DHB
- Hospice Waikato would require additional resource if this service was transferred
- Limitation of DSS knowledge and/or relationship with RH/CC in term's of transitioning from personal health to DSS when patients exceed contractual timeframes and need to transfer between contracts.

It was recognised that a couple of the options considered were outside the scope of the project, but have been included as possible opportunities for consideration in the future.

Option Five

Option five considers Rural Hospitals and Community Based Services, Acute Home Support Services managing the palliative care support services. The advantages of this option are:

- Smooth transition for those palliative care patients and family / whānau that have accessed from Acute Home Support services and transition to palliative care support services
- Acute Home Support services do access carers for family / whānau and/or DNs

The disadvantages of this option are:

- Limited resource, reliance on one person to provide the service (with DNs providing leave relief for the current incumbent), therefore additional resource would be required
- Should the current incumbent leave there is a risk of limitation of DSS knowledge and/or relationship with RH/CC in term's of transitioning from personal health to DSS when patients exceed contractual timeframes and need to transfer between contracts
- Historically attempts to integrate / collaborate between Acute Home Support and DSL were not realised.

On consideration of the advantages and disadvantages this option is not recommended. The change management required and the dependence on one person to provide the service largely outweigh the perceived benefits with this option.

Option Six

Option six considers a one stop shop concept to integrate both personal health (palliative care, acute home support) and disability support services for the Waikato DHB. DSL would manage and administer the range of contracts.

Development of this option would involve Planning and Funding, DSL, Acute Home Care Support, and potentially Hospice Waikato. This model requires the various systems/ processes, funding streams and services to connect with each other, by combining contractual and funding arrangements and / or by the development of close working relationships.

A 'one stop shop' is envisaged for referrals to simplify the process for referrers and clients / families and facilitate a seamless service provision. Linking these funding streams and their services would eliminate the current confusion and disputes over boundary issues.

Included in option six is the concept that carer support services would be contracted by the service holder so that referrers / families are not required to find a carer once approval for carer support night / day relief has been granted. This option has resource implications and implementation would be dependent on resources becoming available in the future.

Consideration should also be given to extending the eligibility for services from the last six weeks of life to the last 85 days (refer Canterbury Health's package of care where <8 days was adequate for the majority of clients accessing their "End of Life" Support Care Package).

The advantages of this option are:

- A one stop shop approach for community based support services for the Waikato DHB
- Adopts a customer approach considering patient and family / whānau needs across the continuum rather provider function / contractual arrangements

The disadvantages of this option are:

- No long term resolution to boundary issues between personal health and DSD
- Aligning different cultures and change management process would require support to realise this option

Option six is the preferred longer-term option for the Waikato DHB, but this options is outside the scope of the project and would require further analysis.

Table three further details the six options and considers components essential to the management of a palliative care support service.

Table Three – Waikato DHB Palliative Care Support Services Options

Components to be considered in relation to palliative care support services	Option 1 DSL continues to approve & administer palliative care support services funds i.e. Status Quo	Option 2 DSL administers funds but approval given by specialist Palliative Care Co-ordinator	Option 3 PCU approves & administers palliative care support services funds	Option 4 Hospice Waikato undertakes the approval decisions and the administration of fund	Option 5 The Acute Home Care Support Service is expanded to include Palliative Care Support services	Option 6 A 'One Stop Shop' Service Co-ordination concept (includes Palliative Care, Acute Home Support and DSS administrative processes).
1. Necessary skills and expertise to manage approval process	Yes	Yes	Yes	Yes	Yes	Yes
2. Same day processing of applications	Yes	Yes	Yes	Yes	Yes	Yes
3. 7-day a week access to approval of applications	Yes, currently (but not sustainable)	No	No	(?) Yes	No	No
4. Finds/contacts support person for carer support	No	No	No	Yes	Yes	Potentially
5. Advice provided on how to access carers where 4) is not provided	Yes	Yes	?	N/A	N/A	N/A
6. Facilitate assessment for long-term services if required	Yes	No	No	No	Yes	Yes
7. Expertise at budget management via service co-ordination	Yes	Yes	No	Yes	Yes	Yes
8. Potential for budget to be absorbed in other	No	No	Yes	Yes	No	N/A

Components to be considered in relation to palliative care support services	<u>Option 1</u> DSL continues to approve & administer palliative care support services funds i.e. Status Quo	<u>Option 2</u> DSL administers funds but approval given by specialist Palliative Care Co-ordinator	<u>Option 3</u> PCU approves & administers palliative care support services funds	<u>Option 4</u> Hospice Waikato undertakes the approval decisions and the administration of fund	<u>Option 5</u> The Acute Home Care Support Service is expanded to include Palliative Care Support services	<u>Option 6</u> A 'One Stop Shop' Service Co-ordination concept (includes Palliative Care, Acute Home Support and DSS administrative processes).
operating costs						
9. Referrers familiar with process	Yes	No	No	No	No	No
10. Equity of access to support services across the DHB district	No	No	No	No	No	Improved
11. Care co-ordination for palliative care patients	No	Yes	Yes	Yes	No	Yes
12. Addresses confusion with funding boundaries i.e. Personal Health, Disability Support Services, Acute Home Care, and Palliative Care	No	No	No	No	No	Yes
13. Approval decisions and budgetary responsibility with same service	Yes	No	Yes	Yes	Yes	Yes
14. Consistency of approval decisions	No	Yes	Yes	Yes	Yes	Yes
15. Service is reliant on	Semi	No	No	No	Yes	No

Components to be considered in relation to palliative care support services	<u>Option 1</u> DSL continues to approve & administer palliative care support services funds i.e. Status Quo	<u>Option 2</u> DSL administers funds but approval given by specialist Palliative Care Co-ordinator	<u>Option 3</u> PCU approves & administers palliative care support services funds	<u>Option 4</u> Hospice Waikato undertakes the approval decisions and the administration of fund	<u>Option 5</u> The Acute Home Care Support Service is expanded to include Palliative Care Support services	<u>Option 6</u> A 'One Stop Shop' Service Co-ordination concept (includes Palliative Care, Acute Home Support and DSS administrative processes).
one person						
16. Service provided across DHB region	Yes	Yes	Yes	No	Yes	Yes
17. Extra resource required to provide service	Yes	No	Yes	Yes	Yes	Yes

RECOMMENDATION

It is recommended that the General Manager, Health Services approve the following recommendation and that in partnership DSL and the Waikato Palliative Care Operations Network lead the implementation of the recommendations within the 2006-07 year. It is recommended that:

- DSL remain the lead provider that manages and administers the palliative care support services contract for the Waikato DHB. The following improvements to the current systems and processes will be implemented to enhance the quality of the service:
- The proposed eligibility criteria, assessment and referral tool and guidelines are approved and implemented. Training and information is provided to referrers on the new tools and guidelines
- DSL use increased funds to employ a 0.5 fte service co-ordinator
- PCU continue to provide DSL clinical support and guidance
- DSL explore the option and benefits of referrals routed through the Referral Co-ordination Centre
- Improved data collection through the development of a minimal data set
- Waikato DHB planning and funding clarify with DSL contractual reporting and monitoring requirements in relation to palliative care support services
- Waikato DHB planning and funding clarify with Hospice Waikato contractual requirements in relation to night and day carer relief.

A longer-term recommendation to increase access to palliative care support services firstly to meet the timeframes of:

- The New Zealand Palliative Care Strategy (2001) of twelve months and
- The New Zealand Cancer Control Action Plan (2005) timeframe of any stage after diagnosis of a life-threatening illness

will require significant investment. Additional funding would need to go through the Waikato DHB prioritisation process and be phased in over a 5 – 10 years.

IMPLEMENTATION PLAN

Objective	Specific Tasks	Responsibility	Timeframe	Milestones/ Measures
Waikato DHB Palliative Care DSL Review Project Report endorsed and recommendation approved	<ul style="list-style-type: none"> Final plan submitted to Waikato Palliative Care Operations Network for endorsement 	Jan Hewitt	Sept 06	<ul style="list-style-type: none"> Plan endorsed by Operations Network
	<ul style="list-style-type: none"> Report and recommendation approved 	Jan Adams	Oct 06	<ul style="list-style-type: none"> Recommendation endorsed by GMHS
To employ service co-ordinator	<ul style="list-style-type: none"> Position description prepared and recruitment request approval obtained Employ service co-ordinate 	DSL Manager	Oct 06	<ul style="list-style-type: none"> Service co-ordinator employed
To implement the: <ul style="list-style-type: none"> entry criteria referral assessment tool allocation guidelines 	<ul style="list-style-type: none"> Submit the new documents to the forms committee for approval Arrange printing of new forms 	DSL Manager	Oct 06	<ul style="list-style-type: none"> Forms approved and printed
	<ul style="list-style-type: none"> To educate and communicate with referrers the implementation of the reviewed criteria, tools and guidelines i.e. GPs, RH/CC facilities, DNs, Hospice, PCU and other hospital sites 	DSL Manager	Oct 06	<ul style="list-style-type: none"> Improved understanding by referrers and transparency re accessing palliative care support services.
	<ul style="list-style-type: none"> Distribution of the new referral/assessment tool and allocation guidelines to referrers 	DSL Manager	Nov 06	<ul style="list-style-type: none"> New referral / assessment tool used by referrers

Objective	Specific Tasks	Responsibility	Timeframe	Milestones/ Measures
To ensure a single point of entry for palliative care support service referrals	<ul style="list-style-type: none"> To explore the option of palliative care support services referrals routed through the Referral Co-ordination Centre as a Single Point of Entry for referrers. If Referral Co-ordination Centre is adopted as Single Point of Entry resource and processes for data collection is identified 	Service Redevelopment Manager & DSL Manager	Dec 2006 – June 2007	<ul style="list-style-type: none"> Decision is made by 30 June 2007 Associated change management plan is developed by 30 June 2007
To collect relevant data related to palliative care support services	<p>Data on referrals to include:</p> <ul style="list-style-type: none"> Patient details – NHI, name, address, preferred contact, ethnicity, DOB Referrer details - name and designation Provider details – name Referral details - date lodged and date actioned (if different). If referral deemed inappropriate, why and what action taken. Service details – type/level of service approved e.g. carer or respite bed and date service terminated. 	DSL Manager	Oct 2006	<ul style="list-style-type: none"> Data collection is accurate and timely

Objective	Specific Tasks	Responsibility	Timeframe	Milestones/ Measures
To clarify palliative care support services reporting and monitoring requirements	<ul style="list-style-type: none"> Waikato DHB planning and funding clarify with DSL reporting and monitoring requirements in relation to palliative care support services 	Planning & Funding Portfolio Manager's Cancer Control & DSS and DSL Manager	Oct 06	<ul style="list-style-type: none"> Quarterly reports are produced to monitor use and unmet need of palliative care support services. Reports are used to inform future funding decisions/contracts.
To clarify all providers of palliative care support services within the Waikato DHB	<ul style="list-style-type: none"> Waikato DHB planning and funding clarify with Hospice Waikato contractual requirements in relation to night and day carer relief 	Planning & Funding Portfolio Manager Cancer Control & CEO Hospice Waikato	June 2007	<ul style="list-style-type: none"> Service specifications to reflect service provision by 30 June 2007

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APPENDIX 1 – PROJECT PROPOSAL



DEVELOPMENT & SUPPORT UNIT - PROJECT PROPOSAL

Project Name: Waikato DHB Palliative Care Disability Support Review Project

Project Manager: Jan Hewitt, Project Manager, Development & Support Unit

Project Sponsor: Waikato DHB Palliative Care Operations Network

The purpose of this six-month project is to formally review the current DSL palliative care service co-ordination. The goal of the review is that patients in Waikato DHB have improved access and equity of palliative care services.

Background

The Waikato DHB Palliative Care Strategy Project was established December 2004 – July 2005 to oversee a review and development of a plan for the Waikato DHB. The Waikato DHB Palliative Care Strategy Plan 2005 –2010 (August 2005) (Plan) was developed through a process of consultation, review and needs assessment. The aim of the Plan is to provide strategic direction for an integrated and co-ordinated Waikato DHB palliative care service.

Waikato DHB Palliative Care Strategy Plan 2005 - 2010

The aim of the Strategy Plan is to ensure all providers of palliative care in the Waikato DHB work together with the community to ensure that the New Zealand Palliative Care Strategy is implemented in the most optimal way for the Waikato district. This is to ensure that all people with palliative care needs and their family / whānau have access to essential palliative care services, provided in a co-ordinated and culturally appropriate way.

The goal encompasses four key results areas:

1. Integrated and collaborative service
2. Patient focus on improved access and equity to palliative care services based on identified needs and informed choices
3. Workforce development to ensure a skilled and competent workforce committed to the palliative care approach
4. Quality systems

Each of the key results areas have supporting objectives and strategic initiatives recommended for implementation over the next five years.

The Waikato DHB has identified the local issue of accessing night relief throughout the District. DSL currently manages the administration of funds to authorise payment for night carers and access to reshome facilities. This role is by default and there are issues around this service. Hospice Waikato also provide a night relief service within the Waikato DHB region.

The supporting objectives of the Plan for this project are:

Objective 4.5 Waikato DHB planning and funding service should review the Disability Support Link (DSL) palliative care administration function for domicile night relief and respite / end of

life care to resthomes / continuing care.

- (a) Identify if current funding level is adequate and identify appropriate organisation to administer funds.
- (b) Ensure improved access and integrated approach to night relief throughout the Waikato DHB

Objectives of the Project:

- To identify current level of night relief and respite care to resthomes services for recognised Waikato DHB palliative care patients. Identify all service providers. Identify any inequities of access.
- To identify the workload required to support service co-ordination for night relief and respite care.
- Complete a SWOT analysis of the current DSL service.
- Identify if current funding level is adequate and identify appropriate organisation to administer funds.
- To review other models nationally.
- To develop access criteria and guidelines to access the two service components.
- To develop standards, key performance indicators and a data set for reporting and monitoring.
- To recommend the model and plan for the future. The plan will include implications for resources, contracts, financials, timelines and performance measures required.

Key Drivers for the project:

- New Zealand Palliative Care Strategy (2001)
- Health of the Older Persons Strategy (2002)
- New Zealand Cancer Control Strategy (2003)
- The New Zealand Cancer Control Strategy Action Plan 2005 –2010 (2005)
- The Waikato DHB Palliative Care Strategy Plan (2005)

Key Stakeholders:

- Disability Support Link
- Hospice Waikato Community Trust
- Health Waikato Community Service
- Waikato DHB Palliative Care Unit
- Resthomes and continuing care organisations
- Nursing Agencies / NGOs
- PHO's
- Waikato DHB Palliative Care Network (Operations Network and Advisory Group)

Project Structure:

Sponsor: Waikato DHB Palliative Care Operations Network

Steering Group: Waikato DHB Palliative Care Operations Network

Project Group:

Jan Hewitt, Project Manager, Development and Support Unit, Waikato DHB
 Project Officer – Judy Fitness
 Sue Hadlington-Hight, Portfolio Manager Planning and Funding
 Jeff Bennett, Manager Older Persons and Rehab Service

Janice White, Manager DSL

Scope:

- Waikato DHB region
- DSL
- Hospice Waikato

Key Outcomes/Milestones:

- Project commences January 2006
- Project support employed by mid February 2006
- Draft Project Report circulated to Waikato DHB Palliative Care Operations Network early May 2006
- Final Report completed by early June 2006

Method:

- Project Group established
- Employment of Project support for duration of the project
- Consultation with key stakeholders
- Regular project group meetings, minutes circulated
- Background literature search including identification and assessment of alternative models

Resources & Timeframes:

- Project timeframe 1 January 2006 – 30 June 2006
- Project Manager resource from the Waikato DHB Development and Support Unit for the duration of the project
- Project support resource to be funded by Waikato DHB Planning & Funding for the duration of the project

Meetings

- Wednesday 15th February 9 – 10am
- Wednesday 15th March 9 – 10am
- Wednesday 12th April 9 – 10 am
- Wednesday 17th May 9 – 10 am
- Wednesday 14th June 9 – 10am

Venue

- Waikato DHB Interview Room or DSL

APPENDIX 2 – DSL PROCESSES & GUIDELINES (1999)

1. DSL Acceptance Criteria for Assessment

ACCEPTANCE CRITERIA FOR ASSESSMENT

Clients will be accepted for registration if:	
	1. They have a terminal condition requiring palliative care and are most likely to die within the next 3-6 weeks
and	2. They do not fit the Ministry of Health Definition of Disability
and	3. They have a full-time carer (unpaid) Or They have a live-in carer who provides a minimum of 4 hours per day of care (unpaid)
and	4. The client would require a change of living circumstances if support were not provided
and	5. A referral has been received from: <ul style="list-style-type: none"> • Hospice • Oncology Resource Nurse • Oncology Social Worker • A Health Practitioner/ Health Service

*** Palliative care is a term used to define the care that is offered to patients with active, progressive, advanced disease which is unresponsive to curative treatment.**

****** A disability assessment is inappropriate for any client with a terminal illness. Therefore Disability Support Link would need to request that a **nursing report** outlining care requirements is completed only if there is a need to provide registered nurse support and funding.

2. DSL Palliative Respite Care and Palliative Care Where Client Requires Rest Home Admission

PALLIATIVE RESPITE CARE	
PHILOSOPHY	<p><i>To provide a responsive appropriate service that assists clients and their families to maintain the client at home, providing respite (time out) for caregivers during the last few weeks of life.</i></p> <p>To provide a service that is integrated with the total client management and that optimises options for a dignified death.</p>
SPECIFIC TASK OF SERVICE	<p><i>To:</i></p> <ul style="list-style-type: none"> • Ensure the access is simple and straightforward • Ensure the processes define palliative care category of clients • Ensure the service is responsive • Ensure access is timely • Ensure correct invoicing and payment of relief carers <p>For clients living alone –</p> <p>As Palliative care is primarily to be used as carer support, for those clients living alone, a nursing report is to be forwarded when care is required.</p> <p>No SNAP is needed.</p>

PALLIATIVE CARE WHERE CLIENT REQUIRES REST HOME ADMISSION	
PHILOSOPHY	<p>To provide a responsive appropriate service that assists clients and their families</p> <p>To provide a service that is integrated with the total client management and that optimises options for a dignified death.</p>
SPECIFIC TASK OF SERVICE	<p><i>To:</i></p> <ul style="list-style-type: none"> • Ensure the access is simple and straightforward • Ensure the processes define palliative care category of clients • Ensure the service is responsive • Ensure access is timely • Ensure correct invoicing and payment of relief carers

APPENDIX 3 – DSL DATA ANALYSIS

Data was analysed to identify:

- volumes per referral type (Table one)
- referral types received by DSL from Hospice Waikato (Table two) and
- referral types per financial year 2001-02 to 2005-06 (Chart 2).

Table One: Number of Referrals by Source, 01 July 2001 – 30 June 2006

Requests	Volume	Ave/Year	Ave/Month
Palliative Care Carer Support	381	76	6.3
End of Life/Respite Beds (Hospital)	344	69	5.7
End of Life/Respite Beds (Rest Home)	96	19	1.6
Palliative	59	15	1.2
*Undefined	40	8	0.4

Data source DSL (2006 projected volumes based on Jul-Mar data)

*Undefined is assumed to be predominantly for palliative care carer support night/day relief because approval for respite beds necessitates fuller referral information.

Table Two: Number and type of referrals received by DSL from Waikato Hospice

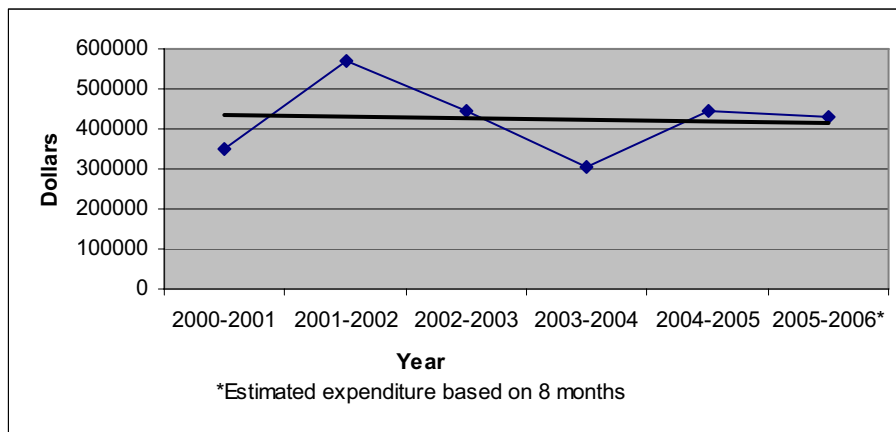
Financial Year	# Rest Home/Continuing Care Referrals	#Carer Support Referrals
2001-02	0	2
2002-03	2	0
2003-04	5	0
2004-05	8	6
2005-06*	2.6	13

* Projected volumes based on 9 months data (Jul-05 to Mar-06). Data source DSL

The reason for the variation in referral behaviour is unclear but Hospice Waikato indicated that access to their Hospice community inpatient beds is monitored more closely now than previously to ensure appropriateness of referrals. It is also possible that the introduction of palliative care initiatives have had an impact by reducing hospital admissions but increasing the need for carer support.

DSL's invoiced expenditure by for palliative care support services per financial year is shown in Chart one.

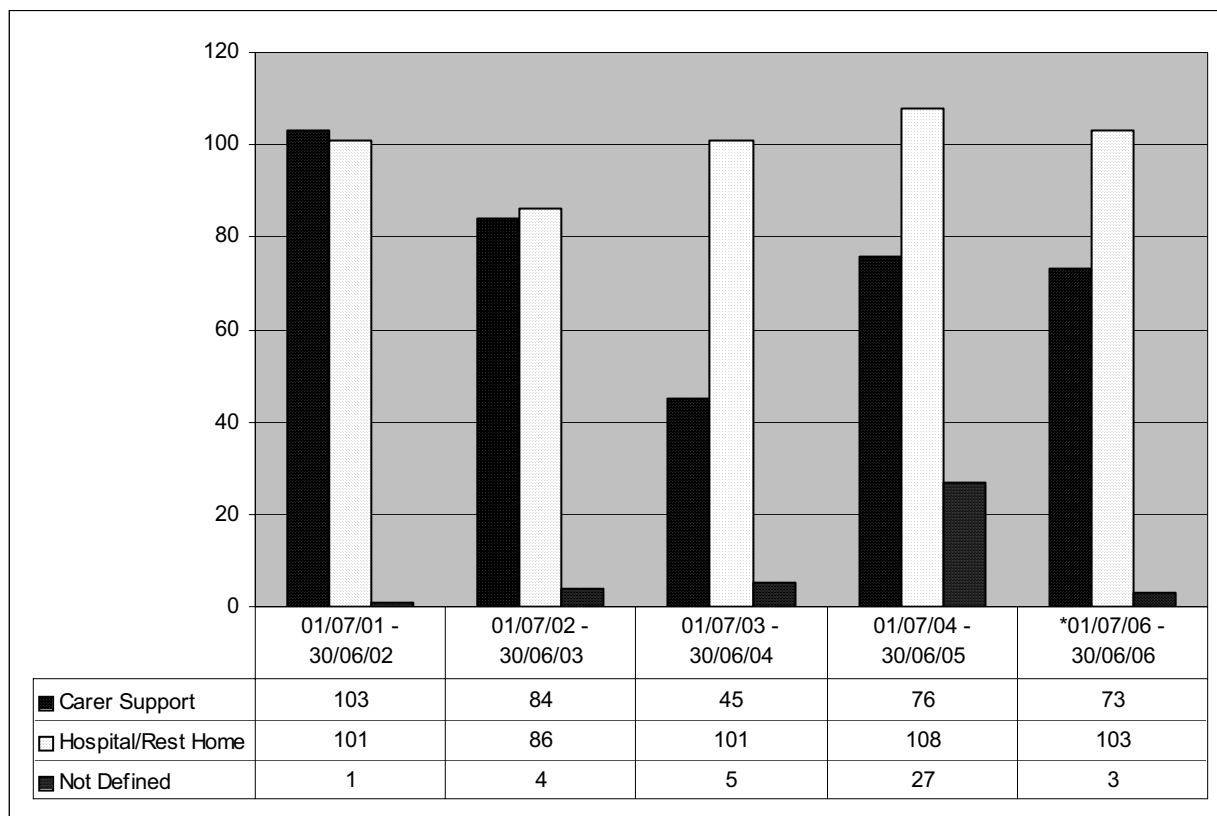
Chart One: DSL invoiced palliative care services per financial year 2000 – 2006 per year



Data source DSL

Chart two illustrates types of referrals (all sources) approved per financial year from 2001 to 2006. The last three years have shown an increasing use of respite/‘end of life’ beds and decreasing use of carer support night/day relief whereas in the 2001-02 and 2002-03 years their use was equal. The reduction in the use of carer support night/day relief may be more a reflection of lack of availability of carers than a decreased need.

Chart Two: Palliative care referrals approved by DSL per type and financial year

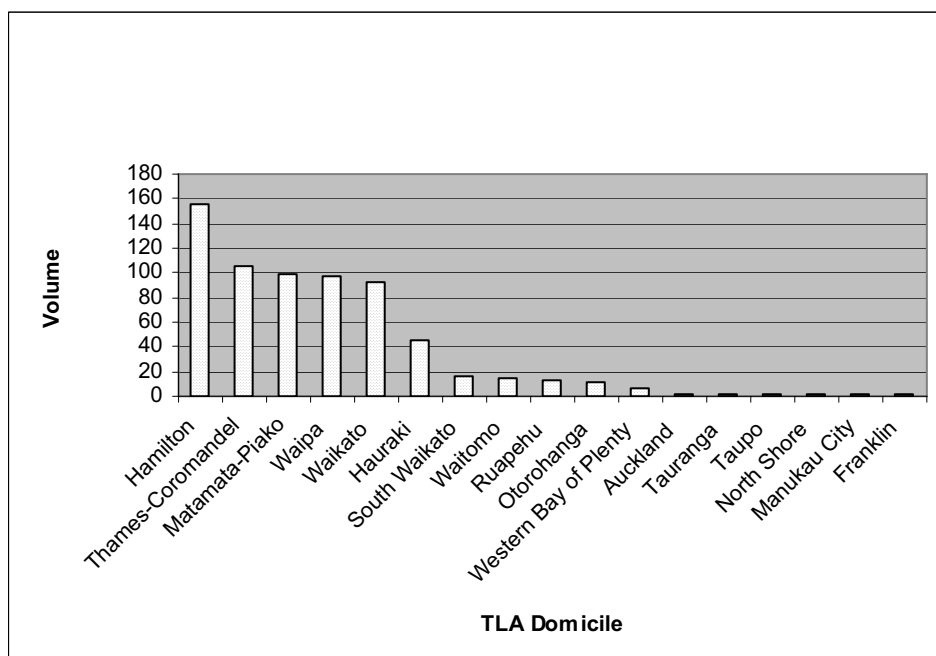


Data source DSL

NHI numbers for patients who had received palliative care support services from 2001-02 to 2004-05 financial years were cross-referenced to data from Waikato DHB Costpro system to obtain demographic information on age, ethnicity, domicile Territorial Local Authority (TLA) and deprivation index. 29 (4%) of patients could not be cross-referenced.

Chart three shows DSL Palliative Care Approvals by domicile TLA – Hamilton has the largest volume volume (155) with Thames-Coromandel, Matamata-Piako, Waipa, and Waikato TLAs all having approximately two-thirds of Hamilton’s volumes. Charts four and five illustrate DSL referrals by ethnicity and deprivation rate.

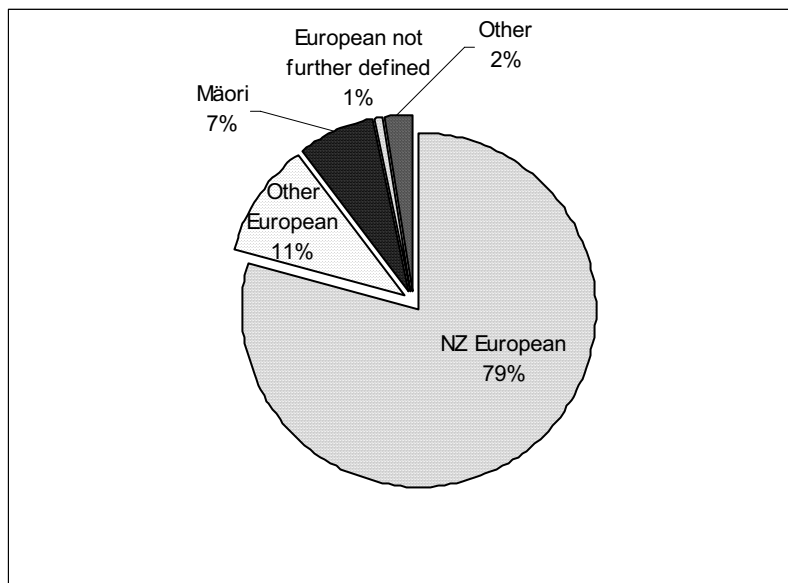
Chart Three: DSL palliative care approvals by TLA, 2001-2005



Data source DSL data cross-referenced to Waikato DHB Costpro

The greatest users of the service by ethnicity are NZ Europeans, followed by ‘other Europeans’ and Māori.

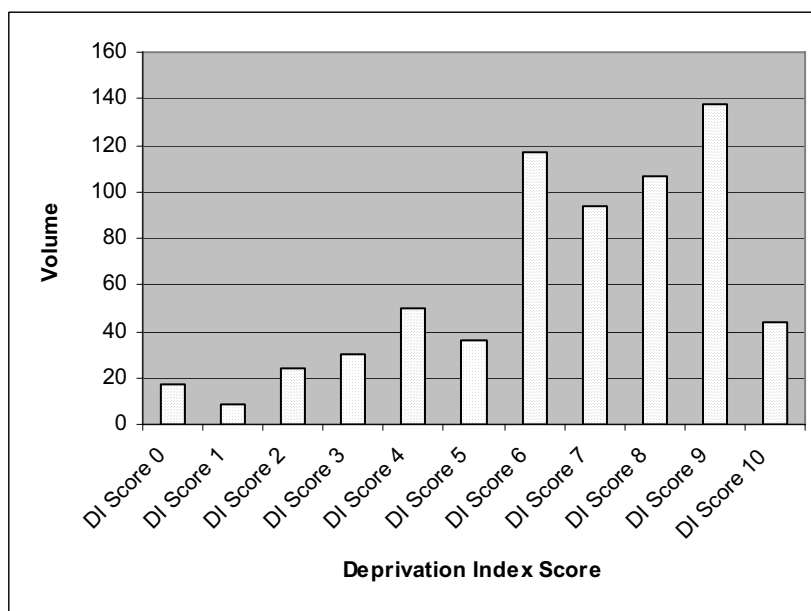
Chart Four: DSL Palliative Care Approvals by Ethnicity, 2001 - 2005



Data source DSL database cross-referenced to Waikato DHB Costpro

Deprivation rate index scores of six to nine received palliative care support services more frequently than those living in areas with a low deprivation rate.

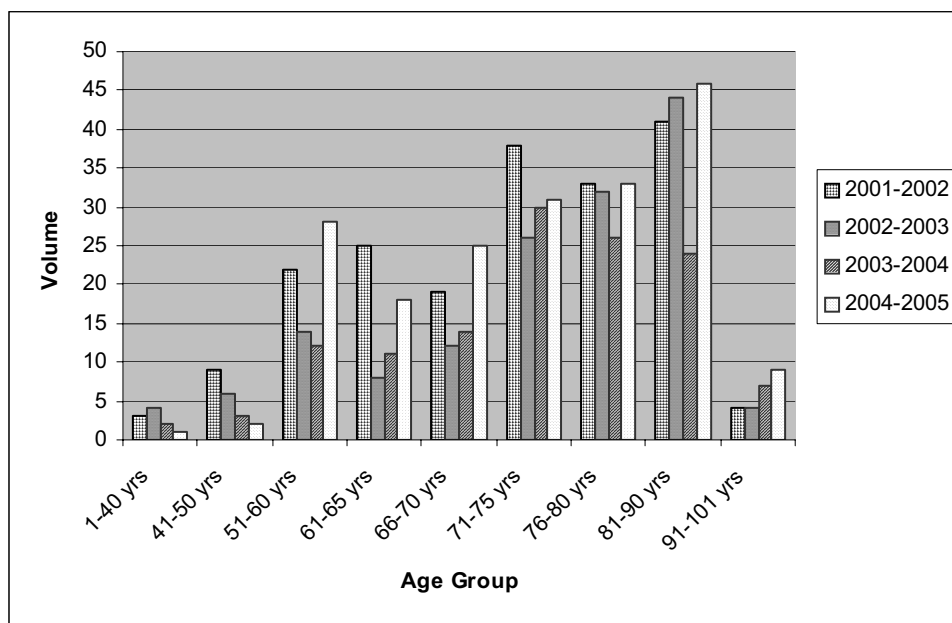
Chart Five: DSL Palliative Care Approvals by Deprivation Index, 2001 - 2005



Data source DSL database cross-referenced to Waikato DHB Costpro

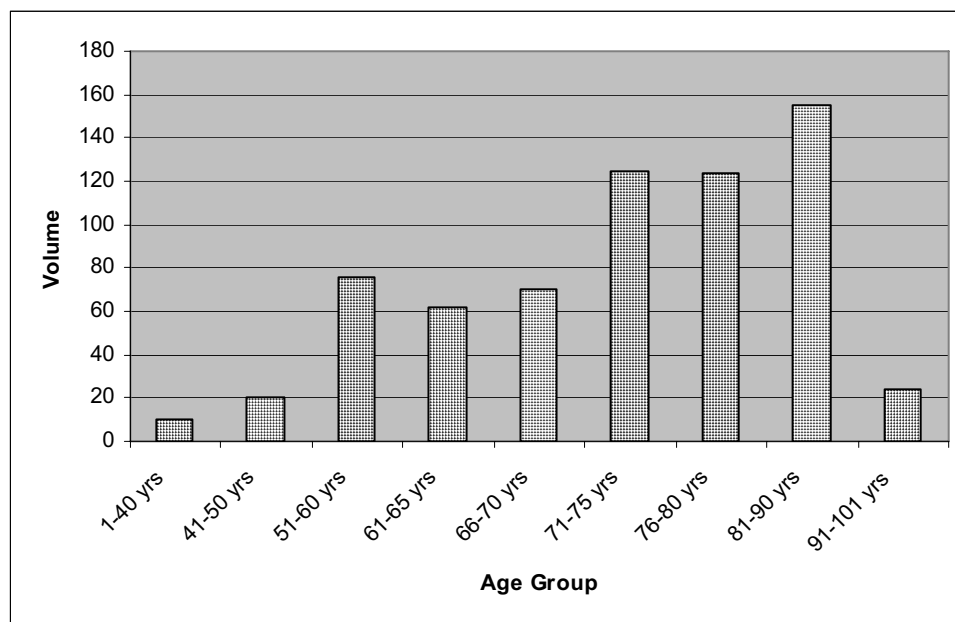
Charts six and seven consider DSL palliative care approvals by age and financial year. Unsurprisingly, most referrals were for the older age groups i.e. 71– 90 year olds.

Chart Six: DSL palliative care approvals by age & financial year



Data source Waikato DHB Costpro

Chart Seven: DSL palliative care approvals by age, 2001to 2005 (financial years)



Data source Waikato DHB Costpro

APPENDIX 4 – S.W.O.T. ANALYSIS

Strengths

- Single point of entry for palliative support services
- DSL Manager and two senior staff's knowledge & experience with the decision-making process for palliative care funding
- DSL has proven invoicing and processing systems
- Guidelines have been developed to assist staff
- DSL has good working relationships with other stakeholders e.g. Palliative Care Unit, GPs, DNs, Hospice, etc encourages co-ordination of services
- PCU supports DSL manager with clinical guidance when required
- Same day processing of applications for palliative care support
- 7-day a week access to DSL manager for approval of applications
- DSL databases (Access and spreadsheet for invoicing) can provide reports on use / costs
- DSL provides advice to referrers on how to access carers for Palliative Care Carer Support
- DSL can facilitate assessment for long-term services if this is necessary
- DSL has expertise at budget management via service co-ordination
- Data demographics indicate low socio-economic patient/families/whānau are accessing these services.

Weaknesses

- Current definitions and eligibility criteria for palliative care support services (DSL for six weeks and Hospice for six months) are not congruent with either the:
 - The New Zealand Cancer Control Strategy Action Plan (MOH, 2005) that aligns with the World Health Organisation (WHO, 2002) definition that “the provision of palliative care is applicable at any stage after diagnosis of a life-threatening illness, and not at the very end of life (terminal phase)” or the
 - New Zealand Palliative Care Strategy (2001) recommendation that palliative care should generally be available to people whose death from progressive disease is likely within 12 months
- Current eligibility criteria for accessing palliative support services are not formalised, creating uncertainty for referrers
- Integrity of referrals – anecdotally, referrers ‘weight’ to obtain funding approval
- Lack of clarity for referrers re entry and exit criteria for funding approval
- No formal assessment by designated assessor/s and lack of agreed assessment tool
- Inequity of services – DSL patients not registered with Hospice Waikato can only access support services through DSL. Hospice Waikato patients are able to access palliative

support services through contracted services at both Hospice and DSL. Service specifications are out of date and not reflecting the services provided

- Family/DN have responsibility for finding carer support person for night relief
- Inequity of access to support services across the DHB e.g. night relief carer support, Hospice Community Inpatient beds
- Access to services, particularly palliative carer support night/day relief is not equitable across the Waikato DHB district due to variable availability of carers
- Inconsistencies with provision of palliative care carer support night/day relief i.e. DSL approves the funds but does not provide the personnel (although will advise) whereas Hospice Waikato will organise the carer
- Data collection is incomplete with minimal monitoring services
- Nationally it is known there is fragmentation, gaps and issues related to the boundaries of personal health and disability support services and the needs of people with long-term, chronic illnesses
- Limited numbers of DSL staff with the necessary knowledge & experience to assess information and approve referrals
- Level of need unclear – managed by budget rather than patient and family/whānau need
- Palliative Care funding does not include high-cost dressings, high-cost medications, or extra GP visits (refer to Palliative Care Strategy Plan), issue when patient admitted for respite care
- Access database incomplete and minimal use of the data for reporting and monitoring
- No identified care co-ordination for palliative care patients (refer to Palliative Care Strategy Plan)
- No existing directory of palliative care support services available in the region (refer to Palliative Care Strategy Plan)
- Confusion between DSL and Planning & Funding on contract
- Use of GP Acute beds as substitute for night relief carer support
- Data demographics indicate limited use by Māori. The reasons for this are unclear but it may be due to inaccurate ethnicity data, or extended family living at home as a carer support payments are not available to a family member living in the same house
- Service specifications out of date (refer to Palliative Care Strategy Plan)

Opportunities

- More effective and flexible support options for patients
- Combine with other approval processes e.g. Acute Home Care Support
- ‘One stop’ shop for support services assessment, funding approval, service allocation, arrangements for care provision
- Clarity on entry and exit criteria and

- Integration with health Waikato's ambulatory Referral Coordination Centre (concept and processes in development).

Threats

- Assessment and approval of funding by another agency.

APPENDIX 5 – HEAT ANALYSIS

1. WHAT HEALTH ISSUE IS THE POLICY/PROGRAMME TRYING TO ADDRESS?

Palliative Care support services to assist people to remain in their homes when they have a life limiting illness.

The support services considered in this review is carer support and respite / end of life care funds administered by Disability Support Link.

To ensure the maximum contribution to improve health and reducing inequalities from its investment in palliative care support services. To address health inequalities for people from population with the poorest health status, such as Māori to gain improved access to palliative care support services.

2. WHAT INEQUALITIES EXIST IN THIS HEALTH AREA?

Current definitions and eligibility criteria for palliative care support services (DSL for six weeks & Hospice for six months) are not congruent with either the New Zealand cancer Control Action Plan (MOH, 2005) that aligns with the WHO (2002) that the provision of palliative care is applicable at any stage after diagnosis of a life threatening illness, and not at the very end of life (terminal phase) of the New Zealand Palliative Care Strategy (MOH, 2001) that palliative care should be generally available to people whose death from progressive disease is likely within 12 months.

Boundary issues between personal health and disability support services for people with long term life limiting chronic illnesses.

Age – under 65 years, accessing long term inpatient / residential care is significant issue for this group (Steering Group Report, 2005).

Geographic – access to rethomes / continuing care facilities throughout the Waikato DHB, may not access organisation of choice. Difficulties accessing carers to support family / whānau, especially rural Waikato.

Socio-economic – if carer is living in same household, funding contribution not available. Funding for carers does not always cover total costs. The proportion of funding decreasing for carer support – moving towards more respite / end of life care. Funding for respite care / end of life may not cover high cost items such as medication, complex dressings.

Ethnic – while it is noted that data integrity is poor. The proportion of Māori that access these support services is less than the palliative care population proportion. Capturing of ethnic data is questionable.

Improve collection and accuracy of ethnicity data in order to improve planning and service delivery for Māori.

3. WHO IS MOST ADVANTAGED AND HOW?

New Zealand European (79%) elderly between the age of 71 –90 years (76%), living in Hamilton.

Palliative care patients under the care of Waikato Hospice in Hamilton, Cambridge and Ngaruawahia. Hospice Waikato provides some carer support with volunteers and respite care. Hospice Waikato also refers to DSL to access these support services.

4. HOW DID THE INEQUALITY OCCUR?

Palliative care support services funding commenced in 1997/98 to meet a 'gap' in services. DSL was requested to administer these funds as they had an invoicing mechanism. At the time there was no eligibility criteria for accessing services. Subsequent criteria were developed in 1999, however this criteria has never been formally recognised. DSL has not had until recently a formalised contract regarding this service, including resources to manage the services. Historically there has been limited monitoring / audit of this service.

The service was not established to include service co-ordination.

Palliative care patients and family / whānau and or health professionals may not always be aware of services (and eligibility criteria) available and how to access.

Waikato DHB up until 2005 have not had a strategic plan for guiding planning and prioritisation of integrated palliative care services.

National and local boundary issues between personal health and disability support services.

Workforce issues with reducing volunteers and / or non-regulated carers available to provide career support.

5. WHAT ARE THE DETERMINANTS OF THIS INEQUALITY?

Access to services, age, geographical, broader health determinants i.e. education, low income, low socio-economic, ethnicity.

Ethnicity data quality analysis will be improved for Māori with a disability needs assessment and service co-ordination as required.

6. WHERE/HOW WILL YOU INTERVENE TO TACKLE THIS ISSUE? USE THE MINISTRY OF HEALTH INTERVENTION FRAMEWORK TO GUIDE YOUR THINKING.

Improve access by raising awareness within the community of palliative care support services available.

Improve data integrity to assist with planning future population health needs for these services.

As funds become available access the Waikato DHB prioritisation process to increase access and reduce inequities.

Improve the systems and processes to access these services via DSL.

Actively participate in national developments to address national and local boundary issues between personal health and disability support services.

Māori continue to access mainstream services. These providers have a critical role in improving Māori health and it is essential that mainstream respond effectively to the health status of Māori.

7. HOW WILL YOU ADDRESS THE TREATY OF WAITANGI? HOW WILL YOU ENSURE GOVERNANCE BY, SELF-DETERMINATION BY, AND EQUITY FOR MAORI?

By participating in the Toward Maori Health Gain model

Consulting with Te Puna Oranga with regard to planning services

Development of a Waikato DHB Palliative Care directory of services and providers.

Raise awareness of service with Māori and Pacific health providers.

Participative and effective decision making roles in the health and disability sector.

8. WHAT EFFECT WILL THIS POLICY/PROGRAMME HAVE ON HEALTH INEQUALITIES?

Reduce inequalities through:

Education and marketing of services

Improved systems and processes including transparency of criteria.

9. WHO WILL BENEFIT MOST?

Palliative care patients and family / whānau.

DSL with clarification of service specification components.

10. WHAT MIGHT THE UNINTENDED CONSEQUENCES BE?

Increase in identified palliative care patients and family / whānau requiring support services.

Issues of rationalisation of funding. To ensure other providers work effectively together to support initiatives that positively contribute to the patient and their whānau.

No change to the identified population groups that are disadvantaged.

11. WHAT WILL YOU DO TO MAKE SURE IT DOES REDUCE/ELIMINATE INEQUALITIES?

Work in partnership with others to achieve reduction in inequalities.

To have community participation and Māori communities benefit fully from all aspects of care.

12. HOW WILL YOU KNOW IF INEQUALITIES HAVE BEEN REDUCED/ELIMINATED?

Future data used for monitoring and planning services.

Improving access to services and education will lead to a reduction in the inequalities.

Good networks.

APPENDIX 6 – FEEDBACK

Community Feedback

Consultation with stakeholders included feedback from:

- Survey of district nurses,
- Focus group with some continuing care providers
- An AGEWISE meeting.

Findings of the consultation are briefly discussed.

District Nurse Survey of Palliative Care Support Services

A survey was distributed to district nursing bases to determine if there was variability of access to palliative care support services. Responses were received from nine bases (table two).

Overall, although there was evidence of difficulty accessing palliative care carer support night/day relief in Taumarunui and Otorohanga, survey responses did not indicate that it was a widespread problem, perhaps because alternative strategies are used e.g. GP Acute beds. However, some bases do not refer for carer support night/day relief due to the belief that carers are not available and/or the effort and time taken to locate one.

DNs expressed dissatisfaction with the availability of services in only the last few weeks of life.

<i>Table Two</i>	<i>Number of Patients Application for Palliative Care Support was:</i>		
DNs Base	not sent because of an expectation that it would not be approved	not sent because of lack of carer support /respite beds availability	sent but not approved
Huntly / Te Kauwhata	Nil	Nil	Nil
¹ Whitianga	Nil	Nil	
² Whangamata	Nil	Nil	Nil
³ Matamata	Nil	Nil	Nil
⁴ Waihi	Nil	?	Nil
Raglan & Cambridge	Nil	Nil	Nil
⁵ Hamilton City	Nil	1	1
⁶ Southern & Eastern	Nil	6	Nil

Notes:

¹Whitianga DNs stated there was a need of palliative care night relief for patients who were not in the last few weeks of life. They had not applied for this because they knew the patients did not meet the criteria.

²Whangamata DNs stated that they always negotiate with DSL and usually achieve a positive outcome for night relief.

³Matamata DNs stated that family and friends helped the patient. The funding for night relief from an agency is much less than the agency charges leaving the family to pay the difference. Also, two nights per week is not sufficient for end stage patients.

⁴Waihi DNs state that they haven't requested night relief for years because there are no carers to provide cares, either day or night, so when the family requires relief, the GP admits them to Waihi Hospital for a week in a GP Acute bed.

⁵ Hamilton DNs indicate respite bed not always available at rehome of choice, but was available at another facility.

⁶Southern and Eastern DNs indicate access to carer support for both night and day carer relief is not available in Taumarunui and Otorohanga. DNs seldom try to apply for carer support because of shortage of carers in the district. One of the families cited funded their own private nursing relief.

Continuing Care Focus Group

Continuing Care provider representatives from Thames, Coromandel, Whitianga, and Whangamata were consulted regarding their experiences accessing palliative care respite care or carer support. According to these providers, the main difficulty accessing respite/end of life beds was determining when the person was in the 'terminal phase'. Provided the patient met the criteria, and the correct information was provided to DSL, approval was timely. The continuing care providers felt that there was a level of trust between DSL and them that helped the process. However, the perception was that the DSL eligibility criteria had tightened from the last six weeks of life to the last two – three weeks.

Many of the admissions to the continuing care facilities were for symptom control rather than respite care (although sometimes patients would come in for respite because of lack of carer support availability). GPs managed the patient's symptoms with assistance from PCU.

The continuing care providers were unanimous in their praise of the support and advice provided by PCU and cited excellent relationships with the DNs. Hospice was a nonentity for them since it provided no support and did not have a presence in their communities. The local Hospice volunteer group was not affiliated to the Hospice Waikato.

AGEWISE Meeting

Issues raised at AGEWISE meeting were:

- lack of clarity around criteria (geriatrician)
- perception that approval was inconsistent and related to persuasiveness of social worker rather than patient needs (geriatrician) and
- difficulty determining 'terminal phase' especially for medical conditions like end stage cardiac failure.

APPENDIX 7 – OTHER NZ DHBs PALLIATIVE CARE SUPPORT SERVICES

Canterbury DHB and Lifelinks

In July 2005, the Ministry of Health allocated population based funding for Hospice services. Canterbury DHB used this funding to set up Support Care⁵. Support Care is targeted to provide services to patients who have either a severe chronic medical illness or terminal illness (“End of Life” phase based on <86 days to live). Support Care packages vary from low to high, and include carer support and respite care. There is no asset testing for “End of Life” services.

If the patient is still alive after 86 days, he/she is transferred to other contracts i.e. if >65 years of age, transferred to Severe Medical Illness contract (Personal Health) or if <65 years of age, transferred to Lifelinks (DSS Agency) under disability services contract. There can be delay accessing End-of-Life Support awaiting Social Worker assessment.

A Senior Medical Officer documents on the Support Care Application Form that the patient meets the eligibility criteria. A CDHB nominated clinician (list of authorised clinicians available on the Intranet) then competes the signs-off for the application. The patient’s level of need is identified by a needs assessment. Packages support low, medium and high need patients within their home environment. Equipment requirements are identified by Occupational Therapists. The Central Co-ordination Centre (NASC) is responsible for co-ordination of patient’s services and equipment. Carer support night relief or respite care provision can be approved from 14 – 28 days. For further details, refer Canterbury DHB Support Care (Draft) 2005 document.

Capital & Coast DHB

Hospice is funded to provide community and inpatient care with nursing domiciliary care being provided by the DNs. A Respite Care service is available for the last 72 hrs before death i.e. to enable people to die at home if they wish to.

The Care Co-ordination Centre manages the administrative process as the ‘Single Point of Entry’ for Capital Coast DHB but the referral/approval can only be made by a specialist palliative care nurse (either DHB or Mary Potter Hospice) or another member of the Palliative Care Service team.

A number of private providers may provide the respite care but the referrer is responsible for ensuring the appropriateness of the care i.e. nursing skills, equipment, etc.

The Care Co-ordination Centre basically ‘rubber stamp’ the approval but they are responsible for managing the budget (there is a reasonably generous discretionary spending portion in their budget to allow flexibility).

⁵ Canterbury DHB Support Care (Draft) 2005

Counties DHB

Night relief is provided through hospice as part of their contract (COPL0002.3) – the service description states “Night or day carer relief is personal care or nursing care provided in the person’s home for relief of the family/whānau. The type of relief would be dependent upon assessment of the dying person’s clinical needs.” Hospice has responsibility for assessment and care co-ordination.

Lakes DHB and Support Net

There are two systems at Lakes DHB:

- The Rotorua Community Hospice Trust provides night relief in Rotorua as part of their SLA with Lakes DHB. Assessments for night relief are made by the Palliative Care Co-ordinator at the Hospice. The Hospice does not have medical personnel but informally work closely with the Specialist Palliative Care Unit at Waikato DHB.
- Lake Taupo Hospice Trust Inc has only one nursing personnel – the Palliative Care Co-ordinator. All clinical care is provided by the DN service. The Palliative Care Co-ordinator undertakes the assessment and refers for night relief. The DN service and Support Net (NASC agency) share the administrative functions and budget for night relief for Taupo but from 1 July 2006 it will all reside with Support Net.

Night relief has traditionally been organised by the District Nurses in Taupo area who arrange the carers (some are Registered Nurses, some not). Support Net currently pay \$150/night; the rate is historical, based on Cancer Society funding of \$80 and DHB top-up of \$70. The night relief support is only available in the last week/days of life.

MidCentral DHB

The Palmerston North Hospital and Arohanui Hospice are co-located on the same campus. The Arohanui Hospice has 12 inpatient beds, a Palliative Care Specialist and team and provides both domiciliary palliative care and night relief carer support. The hospital palliative care team and the hospice work closely together e.g. the Hospice Clinical Nurse Specialist is based at the hospital and works with the hospital Specialist Palliative Care Team.

Arohanui Hospice fund all carer night/day relief and respite care. A copy of the contract between MidCentral DHB and Arohanui Hospice identified service users as “people who have been diagnosed with a terminal illness for which curative treatment is no longer an option. It is likely (but not always the case) that people utilising the palliative care service will die within twelve months of entry to the service”. COPL 0002.3 Night or Day Carer Relief section states “Night or day carer relief is personal care or nursing care provided in the person’s home for relief for the family/whānau.”

Nelson Marlborough DHB and Support Works

The palliative service does the needs assessment and Support Works (NASC agency) do the service co-ordination, which includes personal cares and household management. The hospice organises respite – usually in an inpatient unit. Resource for night relief used to come from Cancer Society funding and the hospice would organise it too (if still available). Palliative care is a separate budget: Support Works receives a management fee and reports against the budget.

Support Works also process residential bed placements – short-term, i.e. up to 10 days, is ‘free’ and then reviewed whereas long-term is the same as disability clients and are subject to asset and income testing from day 1 of admission. If the client is already a disability client and has a package (e.g. motor neurone disease), that package continues. So some clients may have access to respite which could be used in a residential setting or at home for a full or part day, or overnight if that is their choice and can be resourced.

Otago DHB

Hospice is contracted under specifications to provide palliative care night/day relief and respite care (7 days ‘end of life’). The hospice doesn’t often provide a respite care service to rural clients. A new 12-bedded facility has been built and Hospice seems to focus more on use of the facility, i.e. admissions to it, than providing care in the community.

Personal Care can be accessed under the ‘old’ system – for a maximum of 28 days. Funding is bundled up with Carer Support for Aged People and for Young People with Mental Health problems. Only specialists (who delegate authority to Social Workers) or GPs (who always apply for the full 28 days regardless of need) can make requests for Personal Care.

Wairarapa DHB

Palliative Care night relief is currently provided through the Cancer Society but a recent palliative care review has indicated that it should be contracted with other hospice work. Both the district nursing service and the hospice contact the Cancer Society for approval of a particular person (usually a registered nurse) for night relief. Night relief is generally for 3 nights only but may be extended. The Cancer Society pays the nurse providing the night relief directly rather than through the family.

Chronic Medical Illness funding is managed by Focus (NASC agency) and they approve respite beds of up to 6 weeks. They have done a ‘one-off’ arrangement for a particular patient where a residential care provider has been given a budget to provide a package of cares e.g. respite, night relief, whatever is best suited to the needs of the person. NASC liaises closely with the provider and there have been clear goals/outcomes determined for the patient.

Waitemata DHB

Recently the Personal Health support services and NASC services have been amalgamated:

- Personal Health now covers everyone <65 years, and includes younger palliative care patients.
- All >65 years are funded through Disability Support Service.

If an existing DSS client develops new needs as a result of a palliative care condition, a package is developed to meet those needs and may include night relief, or time in hospital. The DHB contracted carers do not have night relief included in their contract so private providers are used to provide this service. Approximately 50% of Personal Health clients have palliative care needs. A package is developed for these clients, based on needs and so may include overnight care in a facility, night relief, or whatever is deemed appropriate.

Hospice services in the region are somewhat fragmented with inpatient beds available in North Shore but only used for symptom control so if these are full other beds need to be accessed to meet client needs. All patients undergo a needs assessment – the same tool is used for all clients but because the tool is not clinical it isn't too problematic that it is the same tool. Personal Health and NASC service work closely with clinical staff to ensure an appropriate package of services is developed.

APPENDIX 8 – PROPOSED ENTRY CRITERIA, REFERRAL / ASSESSMENT & GUIDELINES

2006 Entry Criteria for Palliative Care Funding

Palliative Care Support Services consist of:

- a) Night / Day Carer Relief or
- b) Respite / End of Life inpatient facility bed.

Due to funding limitations, high and medium needs-based¹ packages of care will be given priority – refer Allocation Guidelines.

(¹Needs is the requirement for support where demands placed on the patient and primary carer / family exceeds their available capacity for self care.)

Client Group

- The client is in the ‘terminal’ phase and not expected to live beyond six weeks.

Entry Criteria:

- Clients are within the Waikato District Health Board district
- Are referred by:
 - Palliative Care Unit
 - Health professionals involved in the Collaborative Care model
 - Other Waikato District Health Board staff e.g. hospital and
 - Hospice Waikato or
 - General Practitioners who have deemed their patients are “palliative” i.e. no more active curative treatment available
- Referred using the Palliative Care Referral / Assessment form. This form must be fully completed to ensure there is adequate information to enable the decision to be made regarding the appropriate level of care.

Exclusions

Patients actively accessing Hospice Waikato home-based / inpatient community services.

2006 Palliative Care Referral / Assessment

SURNAME: _____ **NHI:** _____

FIRST NAME: _____ **DOB:** _____

ADDRESS: _____ **PHONE:** _____

GP: _____ **CLINICIAN:** _____

CLIENT CONSENTS TO REFERRAL: Yes / No

ETHNICITY _____ **CSC : Yes / No**

CLIENT'S PREFERRED CONTACT PERSON:

NAME: _____

ADDRESS: _____

PH: *Home:* _____ *Work:* _____ *Mobile:* _____

RELATIONSHIP: _____

DIAGNOSIS:

HISTORY AND REASON FOR REFERRAL TO PALLIATIVE CARE:

SOCIAL SITUATION:

SENSES AND COMMUNICATION:

Palliative Performance Scale (PPSv2) –
Victoria Hospice, Australia - version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity <i>with</i> Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

ALLERGIES / SENSITIVITIES:

MEDICATIONS: (List of current pharmacy)

Self administered: Y/N OR (indicate administration) _____

TREATMENT / DRESSINGS:

APPOINTMENTS / FOLLOW-UPS FUTURE CARE:

COMMENTS:

REFERRER NAME: _____ **PH:** _____ **FAX:** _____

SIGNATURE: _____ **DATE:** _____

NAME (Please print) _____

DESIGNATION: _____ **SERVICE/WARD:** _____

2006 Palliative Care Service Allocation Guidelines

SCALE	DESCRIPTOR	OUTCOME	ALLOCATION
Very low 100-90%	<ul style="list-style-type: none"> The patient is diagnosed and either undergoing treatment or Stable and requiring little or no support from others. 	<ul style="list-style-type: none"> Information about resources available is given. Referrals to D/N, Hospice, Cancer Society facilitated by GP 	Nil
Low 80-70%	<ul style="list-style-type: none"> Although coping, the patient's ability to be fully independent and maintenance of life skills is compromised. 	<ul style="list-style-type: none"> The patient is supported in ADL's as required. 	Nil. Suggest referral to acute care services for home care support.
Medium 60-50%	<ul style="list-style-type: none"> Functional skills and well being are deteriorating. Active treatments may still be in place. Their family/spouse/partner are under considerable pressure and their ability to support the patient is compromised. Clients receiving Homebased care through Hospice are only eligible for this level of care once Hospice provision of care has been utilised and then only for a maximum of 5 weeks. 	<ul style="list-style-type: none"> The patient's support services maximises their safety and well being. The carer has access to carer relief that enables them to maintain their well being. The patient continues to be able to be supported at home. Specialist treatment and services are accessed as required. 	<ul style="list-style-type: none"> Up to \$150 a week. (e.g. 2 nights relief or support during the day to give carer a break). Acute care services for ADL's may still be in place.
High 40-20%	<ul style="list-style-type: none"> Family/natural support is significant Cancer Society/Hospice may be accessed for psycho/social support. Counselling services accessed as required. 	<ul style="list-style-type: none"> The carer/family have increased access to support services to enable them to continue to care for patient at home if desired. May include private nursing agency staffing and may require awake staff and RN care. Access to other support is facilitated. 	<ul style="list-style-type: none"> Up to \$360 per week. Acute care ADL's may increase. Care relief is accessed more frequently and if required through nursing agencies (will need co-ordinator agreement).
Very High 10-0%	<ul style="list-style-type: none"> The patient's ability to remain in community is compromised due to complex support needs. Due to significant deterioration, the patient requires a high level of care. Current support is no longer able to be maintained or appropriate The safety of patient and carer is at risk. 	<ul style="list-style-type: none"> Resthome/continuing care for respite or end of life care. End of life care patients will have 2-weekly reviews to determine if transfer via NASC required. 	<ul style="list-style-type: none"> Up to \$650 a week.