Executive Summary

Public consultation on the discussion document “The New Zealand Palliative Care Strategy” was held between July 2000 and September 2000. The document outlined a vision and strategies for the future of palliative care services in New Zealand. 114 submissions were received and a number of public and focus group meetings were also held.

Key findings from submissions, public meetings and focus groups included:

- Support for the definition and principles, vision and essential services outlined in the strategy discussion document, although there were some additional issues identified.

- No clear support for having one provider co-ordinate services. Only 51.8% of submissions agreed that this could work. There was support, however, for palliative care services becoming better co-ordinated.

- No clear support for Regional Palliative Care Services. Only 52.7% of respondents agreed that regional services would work. Many of the respondents felt that these functions would be better carried out at the District Health Board level. While some people at public meetings supported regional services and “Centres of Excellence” others were concerned that they should not be developed at the expense of local palliative care services. Some thought that the role of regional services of overseeing the quality and education of local palliative care providers could be carried out at a national level. Many were concerned that links between palliative care services and hospitals should be wider than with Oncology Centres.

- No clear support for Regional Hospital Palliative Care Teams (44.6%). However, many supported the role of the Hospital Palliative Care Team but commented that Hospital Palliative Care Teams should be available in all hospitals and not just tertiary hospitals. Some respondents thought that a palliative care team would be best affiliated with a community/primary care team than an oncology team.

In addition to the above, submissions indicated a need to consider:

- Increased funding for palliative care services and the need for a shorter time frame for implementing the strategy.

- The availability of palliative care services on a 24 hour basis and the importance of access to palliative care services for people in rural areas.

- A greater recognition of the role and funding of the GP in providing palliative care services particularly in rural areas.

- How the needs for palliative care for people with non-malignant disease and children should be met.

- How people who do not fit the DSS definition of disability (for example, those with cancer and multiple sclerosis) access DSS support services including home support and longer term beds, particularly for people under sixty-five. Also, how care can be tailored to meet the specific needs of these people, for example, accredited rest homes were suggested.
• How income support could be made available on a needs basis.
• More education of the public and training of all providers in palliative care.

Māori submissions indicated a need to consider:
• The availability of more information on palliative care services particularly around the time of diagnosis.
• How to increase the understanding of mainstream services on the role of the whānau in caring for dying family members.
• Including Māori providers in the multidisciplinary team. There was support for a Māori care co-ordinator linked to a Māori provider organisation.
• Better co-ordination of services particularly between mainstream and Māori providers.
• The possibility of a pilot project which would provide Marae based palliative care services.
• Training in palliative care for Māori providers.

For Pacific people the issues were similar and include:
• How to increase the understanding of mainstream services on Pacific people's culture and their beliefs in terms of care of the dying.
• How to increase the number of Pacific health professionals working in mainstream palliative care services so that care can be provided in a "culturally safe" way.
• How to disseminate more information on what palliative care services are available to Pacific people.
• How to provide support (both physical and financial) to non-resident Pacific people with family members who are dying.
• Training in palliative care for Pacific people.

The above findings will be taken into consideration in the development of the final strategy document for palliative care services in New Zealand.

Please note that two additional submissions have been received and have not been included in this analysis. The issues raised will, however, be taken into consideration in developing the strategy further. The issues raised are similar to other issues that have been identified.
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Analysis of Consultation

1. Introduction

The consultation process on the discussion document entitled “The New Zealand Palliative Care Strategy” took place between July 2000 and September 2000. Discussion documents were mailed out on July 14 and approximately 1900 copies have been distributed. The discussion document outlines a vision for palliative care and strategies to achieve that vision.

A number of public meetings and focus group meetings around New Zealand were also held to gain direct feedback from the public, providers, carers and people receiving palliative care.

This document provides an analysis of the submissions, public meetings and focus groups. Key findings from the consultation are identified and will be fed into preparation for the final strategy which will be forwarded to the Government for approval.

2. Submissions

This section provides information on the types of respondents (see page 15 for a full list of submitters) who sent in a submission and an analysis of the quantitative and qualitative information received on each question.

Table 1 shows that half (50%) of the 114 submissions came from service providers and organisations. Health professionals and concerned members of the public made up the other 50% of submissions.

The numbers of people that service providers and organisations represented were not always provided in submissions. Numbers that were available showed:

- 16 of the 51 submissions by health professionals represented up to 8 people
- submissions by service providers mainly represented between 1-10 people with two service providers representing 20 people
- organisations provided the least information on how many members they represented. Information that was supplied showed that they could represent up to 21 people. It is likely, however, that some of the organisations would represent more than 21 people.

Table 1: Types of respondents who sent in a submission.

<table>
<thead>
<tr>
<th>Type of respondent</th>
<th>Number</th>
<th>Percentage</th>
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<tr>
<td>Concerned member of public</td>
<td>6</td>
<td>5.3%</td>
</tr>
<tr>
<td>Health Professional(s)</td>
<td>51</td>
<td>44.7%</td>
</tr>
<tr>
<td>Service Provider</td>
<td>40</td>
<td>35.1%</td>
</tr>
<tr>
<td>Organisation</td>
<td>17</td>
<td>14.9%</td>
</tr>
<tr>
<td>Total submissions</td>
<td>114</td>
<td>100%</td>
</tr>
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</table>
2.1 Questions

As most of the submissions were representing more than one person and the number of people involved in a submission was not always identified, the number of yes/no answers for each question is calculated in relation to each submission. As a check, the number of yes/no answers for organisations was also calculated. This showed a similar trend to the overall results.

2.1.1 Question 1

People were asked whether they could identify any further issues related to the provision of palliative care other than those which were detailed in the discussion document. Figure one shows that the majority of respondents (78.6%) identified further issues.

Figure 1: Proportion of respondents who identified further issues related to the provision of palliative care; N=114

Issues identified in response to question 1

A number of additional issues were identified from this question. These include:

- Many respondents identified the need for additional funding for what is seen as a core service and the need for a shorter time frame than the proposed 5-10 years for implementing the strategy.

- Many felt that the needs of rural people were not given enough emphasis in the document. It was noted that there was a need for more palliative care services in rural areas and better co-ordination of services.

- A number of General Practitioners felt that the role and funding of the General Practitioner and other primary care health professionals was not adequately recognised and addressed yet they undertake a large amount of palliative care. The GP was particularly important for after hours care and in rural areas.

- Several respondents stressed the need for appropriate specialist services for children and young people.
• A number of people supported the need to consider those people with diseases other than cancer including those with long-term disabilities. There was also a need to better address the long term palliative care needs among children, young people and those with chronic diseases and disabilities. There were particular problems in obtaining long term care for those under sixty-five.

• Several respondents supported the need to consider support care for family carers.

• A few respondents felt that the care of the elderly was not adequately addressed in the discussion document.

• There was support from a number of respondents for better co-ordination of palliative care services.

• Several respondents supported Māori involvement in the care of their whānau and training for Māori in palliative care.

• A few hospice providers were concerned that the existing expertise and assistance provided by hospices was not adequately acknowledged and should be seen as central to palliative care service provision.

• Several respondents commented that there was a lack of discussion on the role of volunteers.

• Several respondents stressed the need for research into palliative care services.

• Several respondents supported the need for increased palliative care training for providers of both adult and children’s palliative care.

• Several respondents stated that there was a need to base the strategy on the patient’s “right” to palliative care services. It was suggested that the “Code of Rights” could be adopted by the strategy. There was also a suggestion that there was a need for an advocacy service.

• It was suggested by one respondent that there was a need to consider palliative care within the Cancer Control Strategy.
2.1.2 Question 2

This question asked people whether they agreed with the definitions and principles of palliative care. Figure 2 below shows that two thirds (66.1%) of respondents agreed with them and only 7.1% disagreed.

Figure 2: Proportion of respondents who agreed with the definition and principles of palliative Care: N = 114

Comments in relation to question 2

- Most respondents supported the definition and principles.
- Many felt that there was a need to clearly distinguish between the definition of palliative care and the definition of the palliative care approach.
- Approximately twelve respondents argued that there was a need to ensure that the definition ensured that palliative care was available from diagnosis and not just for terminal (or dying) people. If the definition was too rigid it would act as a barrier to continuity of care (for example, transferring between oncology and palliative care services). On the other hand, there were several respondents who felt that a clear definition was important so that “curative” type treatments were not given inappropriately to dying people. Also there was a need to stop medicalising death and to accept death as a normal part of life.
- It was argued by several respondents that there was a need to define the term “hospice”. It was also argued by a few that hospice care should be regarded as integral to palliative care.
- A few respondents noted that there was not a nurse included in the definition of a multidisciplinary team in the glossary.
2.1.3 Question 3

People were asked whether they agreed with the vision proposed in the strategy discussion document. Figure 3 below shows that the majority (72.3%) did agree with the vision. Only 2.7% of respondents did not agree. While 25% of respondents did not identify whether they agreed or disagreed with the vision, their comments were generally supportive.

Figure 3: Proportion of respondents who agreed with the vision for palliative care services
N= 114

Comments from question 3

- Most of the respondents provided comments that were supportive of the vision proposed in the strategy discussion document.
- A few respondents wanted the vision widened as follows:
  - To ensure access to comprehensive, appropriate, accessible palliative care services including those people in rural areas.
  - To cater for people who are not actively dying i.e. those with non-malignant disease that are not curable.
  - To include more than outcomes in the vision statement. It was suggested that following on from the vision there was a need to define quality and undertake performance monitoring. It was argued that we should collect national statistics on the number of palliative care deaths per area per region in New Zealand; number of annual cancer referrals to each hospice/palliative care service compared against the number of annual cancer deaths in the area covered by the service; and the proportion of people who die in each hospice/palliative care service by place of death.
  - To include reference to the community and that care should be provided in or as near to the patient’s home as possible.
- A few respondents argued that the vision should be better termed a mission statement or commitment.
2.1.4 Question 4

Question 4 asks the question of whether the strategy document proposes the right essential services. These include assessment, care co-ordination, advisory and information services, clinical care and support care. Figure 4 shows that nearly two thirds (64.3%) of respondents agreed that these were the right essential service and just under ten percent did not agree. While 25.9% did not answer the yes/no question, they were mainly supportive of the essential services.

Figure 4: Proportion of respondents who agreed that the strategy proposes the right essential services N= 114

Comments related to question four

- Many respondents stated that there was a need for spiritual care, bereavement support and counselling for the whole family.
- Several respondents emphasised the need for flexibility in who the care co-ordinator position should lie with.
- There was support for adding night nursing, and support care to the essential service.
- There were a few respondents that stated the following should be added to the essential services:
  - Day care
  - Complementary therapies
  - Occupational therapy/physiotherapy
- One palliative care nurse specialist put in a whole submission on the importance of publicly funded incontinence supplies for people with cancer. The availability of equipment was also an issue.
- The importance of undertaking research was emphasised by a few respondents.
2.1.5 Question 5

Question 5 asked the question of whether having one provider responsible for co-ordinating and ensuring the provision of essential palliative care services would work.

Figure 5 below shows that just over half of respondents thought this would work. Just over a fifth of respondents felt it would not work. Some of the comments related to this question showed that there was confusion about whether this question was asking about co-ordination of services or the care co-ordinator role.

Many respondents emphasised the need for improved co-ordination between services. Some respondents felt that there was a potential for a conflict of interest if one provider were to “hold the purse” and would result in loss of autonomy for other providers. There would be a need to build and “repair” relationships if this were to happen.

Figure 5: Proportion of respondents who agree that having one provider responsible for co-ordinating care would work: N=114
2.1.6 Question 6

Question 6 asked whether a Regional Palliative Care Service to provide specialist palliative care advice, oversee the quality of palliative care services and education of providers would work. Figure 6 shows that just over half of respondents agreed that a Regional Palliative Care Service would work, just over a fifth of respondents did not agree and 25.9% did not identify whether they agreed or disagreed.

Figure 6: Proportion of respondents who agree that a Regional Palliative Care Service could work: N=114

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<thead>
<tr>
<th></th>
<th>Percentage</th>
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<tr>
<td>Yes</td>
<td>52.7%</td>
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<tr>
<td>No</td>
<td>21.4%</td>
</tr>
<tr>
<td>Not Identified</td>
<td>25.9%</td>
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Comments related to question 6

There were a large number of comments about the role of regional services. Support for regional services was mixed.

- There was a large degree of uncertainty about how regional services would relate to local services and the care co-ordinator role and how they would work with the creation of District Health Boards.
- A large number of respondents felt that the functions for regional services should be carried out at a local or DHB level.
- Several respondents felt that a regional structure would disadvantage rural people and impede necessary diversity.
- Some respondents argued that there should be more than six regional services. Several respondents thought that there was a need for more regional services in the Auckland and Northland area. Invercargill was another area suggested for regional services.
- The three most frequently cited alternative ways of ensuring quality services within the region were:
  - Increased training of existing professionals including GPs and including extra mural courses.
  - There could be regular visits of specialists throughout the region especially in rural areas and the use of buddy systems with GPs.
  - There could be increased use of technology e.g. telephone lines, video conferencing, internet.
A few respondents suggested that quality control should be a national function not a regional function.

2.1.7 Question 7

This question asked whether having Hospital Palliative Care Teams linked to the Regional Oncology Centres would ensure that all hospital providers would have access to specialist palliative care advice. Figure 7 showed that less than half (44.6%) agreed with this question. 22.1% disagreed and 32.1% of submissions did not identify support.

Figure 7: Proportion of respondents who agree that having Hospital Palliative Care Teams linked to Regional Oncology Centres would ensure that all hospital providers would have access to specialised palliative care advice

Comments arising from question 7

- Respondents who agreed with question 7 that Regional Hospital Palliative Care Teams could work thought they would help provide a “gateway” to palliative care services. They could also help to provide education and advice on palliative care throughout the hospital. There would be a need, however, for a good referral system and co-ordination between hospital and palliative care services. It was important that Hospital Palliative Care Teams did not have a medicalised approach. There was a need for palliative specialists to be part of the team. It would be important that these teams were not identified as “discharge facilitators”.

- There were a number of reasons identified for why Hospital Palliative Care Teams would not work. These include the need to have teams based in all hospitals and not just tertiary hospitals; it was suggested that a team affiliated with a community team/primary care unit would be a better linkage than with the oncology team. One respondent felt that there should be a specific palliative team for rural areas. It was suggested that a better working partnership between
hospital and hospice would be all that is needed to improve co-ordination of services.

- There were a number of respondents who voiced concerns about the link to Oncology Centres and the perception that palliative care is narrowly focused on cancer and a medical model. A number of respondents thought that if there were to be Hospital Palliative Care Teams the link needed to be wider than Oncology Centres so as to include those units who care for people with non-malignant disease.

2.1.8 Additional Issues

In addition to the above there were a number of additional issues identified through submissions:

- The need to consider the palliative care needs of dying children.
- Having multiple sclerosis field officers involved in the palliative care of people with multiple sclerosis.
- Including more details on how pharmacy/pharmacists fit into the future of palliative care services.
- Palliative care training for General Practitioners.

2.1.9 Summary of findings from submissions

- 50% of the submissions came from service providers and organisations. Health professionals and concerned members of the public made up the other 50%.
- Two thirds of respondents agreed with the definition and principles outlined in the discussion document. The comments were mainly around the need to differentiate between palliative care and the palliative care approach.
- The majority of respondents agreed with the vision outlined in the discussion document. Comments were mainly around ensuring that the vision catered for people in rural areas and for people with non-malignant disease.
- Nearly two thirds of respondents agreed with the essential services outlined in the discussion document. Most comments were supportive of the essential services.
- While there was no clear support for having one-provider co-ordinate services (Only 51.8% agreed that this could work) there was support for better co-ordination of services.
- There was mixed support for Regional Palliative Care Services. Only 52.7% of respondents agreed that regional services would work. Many of the respondents felt that these functions would be better carried out at the District Health Board Level.
- Less than half of respondents agreed that having Hospital Palliative Care Teams linked to Regional Oncology Centres and Regional Palliative Care Services would ensure that all hospital providers would have access to
specialist palliative care advice. Many thought that Hospital Palliative Care Teams should be made available in all hospitals. Some thought that a palliative care team would be best affiliated with a community team than an oncology team.

2.1.10 Names and Addresses of Submitters

- John Gibson. Executive Officer, Age Concern Wellington (Inc), WELLINGTON
- Beverley Revel, Manager, Hospice HomeCare, Henderson, AUCKLAND
- Suzanne Brocx, Hospice Co-ordinator/Nurse, Hospice Bay of Islands, KERIKERI
- Kerrin Arcus, WELLINGTON
- Eastern Bays Hospice, Glendowie, AUCKLAND
- Peter Buckland, Chief Executive, North Shore Hospice Trust, Takapuna, AUCKLAND
- Elaine Chisnall, CPG Manager, Oncology and Haematology, Healthcare Otago, DUNEDIN
- Kathryn Campbell, PALMERSTON NORTH
- John Carter, Clinical Leader, Wellington Cancer Centre, Capital Coast Health, WELLINGTON
- Rachel Brydon, Co-ordinator, Far North Palliative and Cancer Care, KAITAIA
- Suzanne Russell, Hospice Manager, Southland Hospice, INVERCARGILL
- Fuafiva Fa’alau, Pacific Research Centre, Department of Māori and Pacific Health, School of Medicine, AUCKLAND
- Dr Blair McLaren, Physician/Oncologist and, Drs F Beswick and A Robert, (pain clinic specialists) and, S Williams (social worker), Timaru Hospital, TIMARU
- Robin Williams, Manager and, Deborah Hughes, District Nurse, Community Health Services, Coast Health Care, GREYMOUTH
- Elizabeth Cochrane, c/- Amberley Medical Centre, Amberley, NORTH CANTERBURY
- D Crampton, CHRISTCHURCH
- Jane Hautain, Hospice Trust Board Member, WHAKATANE
- Hazel Hill, Manager, Community Hospice Service, WHAKATANE
- Elaine Dow, South Auckland Hospice, PO Box 560, Manuwera, AUCKLAND
- Joan Carter, Vauxhill, DUNEDIN
- Mrs Pip Egerton, Paroa, GREYMOUTH
- Esme MacDonald - Community Team Leader, Jan McLean - Nursing Team Leader, Dr Garry Nixon - Medical Team Leader, Central Otago Health Services, Clyde, CENTRAL OTAGO
- Kate McKenzie - Senior Social Worker, Palmerston North Hospital, PALMERSTON NORTH
- Jane Patterson, Manager Policy and Support, New Zealand Medical Association, WELLINGTON
- David Ryan, Chief Executive Officer, Otago Community Hospice, DUNEDIN
- Pauline Thwaites, DUNEDIN
- Leslie McCullogh, Associate Director of Nursing, Capital Coast Health Limited, WELLINGTON
Ruth Vincent - National Information Manager, Linda Gray - Field Officer, Taranaki MS Society, WELLINGTON
Patricia Watt, "Bee Block", DARGAVILLE
Dr Robert Cook, Dargaville Medical Centre, DARGAVILLE
Debra Sedgwick, Health Services Manager, Wairarapa Health, MASTERTON
Annie Stroh, Client Service Manager, Quality Health New Zealand, WELLINGTON
Yvonne Boyes, Oncology Resource, District Nurse, Whakatane Hospital, WHAKATANE
Patrick F Fahy, Chief Executive, New Zealand Charter of Health Practitioners Inc, Northcote, AUCKLAND
Mary Mathews, WELLINGTON
Jim Thomson, Chief Executive and Registrar, Pharmaceutical Society of New Zealand, WELLINGTON
Bridget O’Brien, c/- Home Health Care, Middlemore Hospital, AUCKLAND
Colleen Ranford, AUCKLAND
Eileen McKinlay, WELLINGTON
Thames Community Cancer Support Group, THAMES
Cathy Cooney, Service Director, Clinical Support, Lakeland Health, ROTORUA
Associate Professor Margaret Horsburgh, Division of Nursing, Faculty of Medical and Health Sciences, The University of Auckland, AUCKLAND
T.A Joll, Chief Executive Officer, Hospice Wanganui, WANGANUI
Dr Tim Carey-Smith, for South Link Health Inc, DUNEDIN
Dr Kate Baddock, Warkworth Health and Medical Centre, WARKWORTH
Imelda King, c/- Age Concern North Shore, Takapuna, AUCKLAND
Lynda Smith, Auckland Division, Cancer Society of New Zealand, AUCKLAND
Margaret W Guthrie, WELLINGTON
Cassandra Sternoway, Oncology/Haematology Social Worker, Dunedin Public Hospital, Healthcare Otago, DUNEDIN
R L Logan, Medical Director, Hutt Valley Health Limited, LOWER HUTT
Anne MacLennan, WELLINGTON
Kaipara Palliative Care, C/- Josie Scott, Dargaville Hospital, DARGAVILLE
David Ryan, Chief Executive Officer, Otago Community Hospice, DUNEDIN
Karen Foster - Clinical Leader, Desma Dawber - Palliative Care District Nurse, District Nursing Services, Timaru Hospital, TIMARU
Mary Schumacher, Chief Executive Officer, Mary Potter Hospice, WELLINGTON, NZOUTH
John Doggett, Executive Officer, South Canterbury Hospice Inc, TIMARU
Judy Macready, Contract Professional Hospice/Palliative, Care and Health Management, Algies Bay, WARKWORTH
Dr Bruce Foggo, Senior Medical Officer, St Joseph’s Mercy Hospice, Newmarket, AUCKLAND
Ann Moore, CROMWELL
The Trustees and Staff, Te Omanga Hospice, LOWER HUTT
Dr CJ Diggle, Royal New Zealand College of General Practitioners, Devonport, NORTH SHORE
Jane Eyres, Chairperson, Nurses for Children and Young People of Aotearoa, NZNO, WELLINGTON
Dr Anne O’Callaghan, Palliative Care Team, AUCKLAND
Ann Martin, Chief Executive Officer, Hospice New Zealand, WELLINGTON
Sue Morris, Wairau Hospital, Nelson Marlborough Health Services, BLENHEIM
Allan Farnell, Medical Director, St Joseph’s Mercy Hospice, Newmarket, AUCKLAND
Stephanie Waterfield, Chief Executive Officer, Nurse Maude Association, CHRISTCHURCH
Margaret Blake, General Manager, Waipuna Hospice, TAURANGA
Bice Awan, Chief Executive, Skylight Trust, WELLINGTON
Dr David Hamilton, Consultant Oncologist, Wellington Cancer Centre, Wellington Hospital, WELLINGTON
Gaylene Kolodzinski, Palliative Care Nurse Specialist, Waitemata Health, Takapuna, AUCKLAND
Dennis Paget, WELLINGTON
Health Spokesperson, Grey Power Federation of New Zealand, BLENHEIM
Elaine McFelin, Trust Chairperson, The Care Central Trust, DUNEDIN
Dr Anna Holmes, Milton UFS Health Centre, Milton, OTAGO
Ron McInnes, Manager, Hibiscus Coast Hospice, WHANGAPAROA 1463
Te Omanga House, MASTERTON
Dr Simon Allen, Chairperson, New Zealand Branch of the Australia and New Zealand Society for Palliative Medicine, PALMERSTON NORTH
Nelson Region Hospice Trust, Manuka Street, NELSON
Mervyn G Monk, Executive Director, Arohanui Hospice Service Trust, PALMERSTON NORTH
Esther Sweet, c/- Te Omanga Hospice, LOWER HUTT
Helen Sullivan, Co-ordinator for Support and Volunteer Services, Cancer Society of New Zealand, WELLINGTON
Sue Marlow, LOWER HUTT
Teresa Riordan, AUCKLAND
Te Waka Hauora, Health Waikato Limited, HAMILTON
Reverend Theo Carpenter, Health Committee, Kapiti Coast Grey Power Association Inc, PARPARAUMU
Dr K Lum - Medical Director and, Mrs A Robinson - Principal Nurse, Cranford Hospice, HASTINGS
Elizabeth Kelly, INVERCARGILL
Dr Tim Carey-Smith, for Otago Community Hospice, DUNEDIN
Mrs Colleen Moore, Vice-Chair North Otago Hospice Group, Oamaru Hospital, OAMARU
Louise Forsyth, Nurse Manager, Taranaki Hospice Foundation Inc, Westown, NEW PLYMOUTH
Mark Jeffrey, Oncologist, Canterbury Healthcare Ltd, CHRISTCHURCH
Elizabeth Maria Hancy, BAY OF ISLANDS
Adrian Trenholme, Paediatrician, Middlemore Hospital, AUCKLAND
Paula Shepherd, Ministry of Youth Affairs, PO Box 10 300, WELLINGTON
Dr Lorraine Scragg, Total Health Whakatane, WHAKATANE 3080
Merrin Watts, Staff Nurse, Ward 25, Health Waikato Ltd, HAMILTON
Harata Heni Baucke, President, Aotearoa New Zealand Association of Social Workers, Dinsdale, HAMILTON
Jan Mackay, Policy Analyst, Age Concern New Zealand Inc, WELLINGTON
R Thomas, Social Worker, Christchurch Hospital, CHRISTCHURCH
Trish Clark, Rosalie Maaka, Dr Kate Bayslon, Oncology Unit, Southland Hospital,
Jane Wilson - Service Leader Child Health, Child Health Service, Healthcare Otago, DUNEDIN
The New Zealand Home Health Association, WELLINGTON
Richard Hursthouse, Clinical Advisor, Comprehensive Health, Primary Care Organisation, AUCKLAND
Capital Coast Health Ltd, WELLINGTON
Barbara Glenie - National President, Beryl Anderson - National Secretary, National Council of Women of New Zealand, WELLINGTON
Felicity Sidford, Integration Coordinator, Pegasus Medical Group, CHRISTCHURCH
Ann Crawford, Social Work Department, Christchurch Hospital, Canterbury Health, CHRISTCHURCH
Lorraine Sutherland, Senior Social Work Practitioner, Oncology, Social Work Service, Christchurch Hospital, CHRISTCHURCH
Megan Smith, Social Worker, Social Work Services, Christchurch Hospital, CHRISTCHURCH
Kathy Lynch, Debbie Wise, St Joseph's Mercy Hospice, Newmarket, AUCKLAND
Ann Morgan, Dr Kate Grundy, Christchurch palliative Care Team, Christchurch Hospital, CHRISTCHURCH
Janice Donaldson, Manager, Ngai Tahu Development Corp, CHRISTCHURCH
Shona Lawson, Lyttleton, Women's Health Action, New Market, AUCKLAND
Age Concern, WELLINGTON
Peter Woolford, General Practitioner, New Lynn Medical Centre, New Lynn, AUCKLAND
Ministerial Advisory Council for Senior Citizens, WELLINGTON
3. Public Meetings

3.1 Northland 10/8/00

Attendees:
Heather Michaels (Careplus), Cindy Haika (Careplus), Leanne McLiver (Home Support) Tina Darkins (Northaven Hospice), Murray Lints, Jo Loney (Nurse), John Bonetti, (Northaven Hospice), Gay Bonetti, (RD5 Whareora), Margaret Curry (Cancer Society), Naias Nasaverr (Northaven Hospice), Susanne Brocx (Hospice Bay of Islands), Helen Brown (Home Health/District Nursing), Jill Henderson (Home Health care), Josie Scott (Kaipara Palliative care/Dargaville Hospital), Dave Bowden; Laura Lambie and Louisa Ryan (Health Funding Authority).

Key Issues:
- The issue of funding for palliative care was raised at the start of the meeting.
  - One person receiving palliative care services raised the issue of funding inequities across the country. He would like hospices to be funded to a 100% of their operating costs.
  - It was argued by a general practitioner at the meeting that there was a need to have additional funding for primary care services to provide palliative care both for the Whangarei and Kaipara area. This was happening elsewhere in the country and would enable more work by General Practitioners in the community.
  - It was stated that Northland is the poorest region in the country with the biggest employer being the HHS. It was suggested that the way the HHS is funded fragments care.
  - There is a need to ensure that extra funding is available for meeting cultural needs.
  - It was suggested that the maternity funding model could be suitable for palliative care.
  - It was argued that there is a need to ensure that funding recognises the rural population.
  - It was argued that there was a need to have strict entry criteria to ensure sufficient funding for services.
  - It was suggested that the funding should follow the patient.
  - One person asked how the Cancer Society could access funding when the patient did not want to access HHS or hospice services.
- It was stated that Northaven hospice is having increasing referrals for Māori because of the higher profile of the services.
• There was a lot of discussion around the setting up of regional services. It was felt that it was okay to have a centre of excellence in Auckland which links with the Regional Oncology Centre, but that palliative care services should be locally managed.

• There was support for a Whangarei based local palliative care service. Although some people in the Bay of Islands and Far North questioned whether this would work. It was argued that a local palliative care service should include all providers.

• There were some people at the meeting who work in the DSS area who thought that the boundary issues were a problem for people accessing care, both for people with personal health diseases accessing DSS services and vice-versa.

3.2 Auckland 9/8/00

Attendees
Dr A O’Callaghan (Auckland Healthcare); Sharon Knowles(Auckland Healthcare); Lorraine Goodlass (Auckland Healthcare); Jackie Robinson (Auckland Healthcare); Jill Rodgers (Hibiscus Coast Hospice); Ron McInnes (Hibiscus Coast Hospice); Graeme Smith (Nelson Region Hospice); Yvonne Bray (University of Auckland); Noeline Harris (Palliative Care Partnership); Joan Monkton (Eastern Bays Hospice); Mr Alan Earnell (St. Joseph’s Mercy Hospice); Elaine Dow (South Auckland Hospice); Peter Buckland (NorthShore Hospice); Mr K McIver (NZ Charter Health Inc); Jan Nichols; Laura Lambie (Health Funding Authority); Wendy Cook (Health Funding Authority); Tearoha Rahui. (Health Funding Authority).

Key Issues:
• There were a number of questions related to how regional services would work. People felt that in considering regional services there was a need to recognise the needs of smaller places outside Auckland e.g. Kaitaia. Overall there was general support for regional services.

• There were questions related to how the care co-ordinator role would work. There were concerns that it would be like the ACC case management role. The role as proposed in the strategy was explained and overall there was general support for the role of the care co-ordinator.

• The issue of whether there were sufficient longer-term care beds for palliative patients was raised. It was suggested that there was a need to investigate this and identify what the current provision was. It was suggested that there was a need to have more flexible use of DSS funding.

• It was suggested that WINZ should pay for carer support for people taking time off work to care for their loved ones.

• It was suggested that there was a need to ensure that evaluation of the strategy occurred.
• There was a discussion around the cost of home care. It was suggested that home care might be slightly cheaper than hospice care.

• The issue of funding was raised and the fact that hospices are under financial stress.

• The issue of how to better educate the public on palliative care services was raised. It was suggested that pamphlets were not very good. There is a need to consider the best way to disseminate information on palliative care services. It was important that information on palliative care was available at the time of diagnosis.

• It was stated that the Cancer Control Strategy needed to include palliative care as a major part of the strategy, as a large proportion of people with cancer would require palliative care.

• The question of whether palliative care was the correct term and whether an alternative name such as “quality of care” was more appropriate. A number of people felt that the term “palliative care” was important as it described the whole process of care. It was suggested that it was important to change people’s perception of palliative care.

• The issue of how quality of standards would be measured was raised. There was discussion around the role of accreditation. There was also a discussion around the adhoc development of palliative care services and the need to ensure that people were aware of what palliative care services could provide.

3.3 Hamilton 22/8/00

Attendees:
Trish McHugh (Lakeland Health), Doreen O’Conner (District Nurse), Jan White (District Nurse), Steve Smith (Health Waikato), Ian Millward (Waikato Hospice), Graham Callis (Waikato Hospice), Allison Rowe (Waikato Hospice), Jane Hanlson Chris Page (Trevelyn Resthome), Valda Mehrtens (Trevelyn Resthome), Robyn Segedin (One Health Waikato), Des Swanelvelder (Health Waikato), Lyn Lilto (Health Waikato), Margaret Stevenson (Health Waikato), Ann Inglis (Te Aroha Community Hospital), Merrin Watts (Health Waikato), Dot Davies (Health Waikato), Judy Tunnicliffe (District Nurse), Julie Eiles (Community Liaison), Moira Gunnell Waikato Hospital, Rangi Komene (Health Waikato), Harata Bauk (Health Waikato), Julie Biengen (Health Waikato), Glennis Retemeyer (Raukawa Development Trust); Laura Lambie and Elizabeth Bang (Health Funding Authority).

Key Issues:
• The issue of support from the government was raised and whether there would be continued support if there was a change in government. It was stated that both the National and Labour governments supported the development of a palliative care strategy for New Zealand. The meeting generally felt that it was good to
have a strategy for palliative care in New Zealand, although one person argued that the strategy does not put enough emphasis on community care.

- All people at the meeting thought that the strategy would be able to be applied locally and that Hamilton was well set up to co-ordinate and provide local palliative care services and wanted to move ahead with a local plan. The meeting supported the idea of having one local palliative care service budget-holding for palliative care services.

- Most people at the meeting considered having a care co-ordinator role within palliative care services was essential.

- In implementing the strategy it was argued that local palliative care services must be sorted out and funded first before the rest of the strategy.

- It was suggested by the Palliative care specialist at Waikato Hospital (previously a General Practitioner) that the GP should be the care co-ordinator, as the GP is the best person to be the lead in the community and has links with the hospital. Most present argued against this stating that the GP is too busy to be the care co-ordinator and the nurse would be the best person. It was also suggested that General Practitioners could provide the essential services, particularly in the rural areas.

- There were several Māori providers at the meeting and it was suggested that the multidisciplinary team in palliative care services should have a Māori person attached to it. The Māori group liked the idea proposed by the strategy of a local Māori care co-ordinator. It would be important for this Māori person to have support from other Māori as it would be culturally unsafe to have one Māori person working alone.

- It was noted by one person at the meeting that Appendix 7 in the discussion document should include a nurse in the definition of multidisciplinary team.

### 3.4 Wellington 8/8/00

**Attendees:**

Mary Schumacher (Mary Potter Hospice); Ann Martin (Hospice New Zealand); Mervyn Monk (Hospice New Zealand); Rayden Day (Cranford Hospice); Chris Murphy (Mary Potter Hospice); Rod McLeod (Mary Potter Hospice); Belinda Hodge (Mary Potter Hospice); Mary Bingham (Domiciliary Nurse); Jean Parr (Te Omanga Hospice); Beverley Chapel (Advisory Council for Senior Citizens); Biddy Harford (Te Omanga Hospice); Alan Brown (Te Omanga Hospice); Jean Parr (Te Omanga Hospice); Suzanne Hammond (Te Omanga Hospice); Kate Gellatly (Mary Potter Hospice); Pam Diamond (Mary Potter Hospice); Daphne Geisler (Mary Potter Hospice); Kathryn Campbell; Thomas Morgan (Ancillary Service Provider); Deborah Woodley (Ministry of Health); Laura Lambie (Health Funding Authority); Sarah Zino (Health Funding Authority); Sue McTavish (Health Funding Authority).
Key Issues:

- The CEO of Mary Potter Hospice congratulated the Ministry of Health and the Health Funding Authority for working effectively together and developing a good palliative care strategy for New Zealand.

- Questions were raised related to the development of Regional Palliative Care Centres. There was discussion related to how funding agreements would work in relation to District Health Boards. It was stated that Localities/District Health Boards would select Regional Palliative Care Services. Funding for local palliative care services would not be through Regional Palliative Care Centres but through District Health Boards.

- The issue of whether Palliative Care Services would be contestable was raised. There was discussion around the intent of the strategy, which states that palliative care services will build on existing services, and on the government's intent, which is to encourage co-operation and not competition. Also, there was discussion around the fact that palliative care staff are currently employed by existing palliative care services and it would be difficult for new providers to recruit staff trained in palliative care given the limited workforce. It was suggested that the District Health Board’s role would be to contract with organisations including hospices and other palliative care services.

- There were several questions raised related to the care co-ordinator’s role. It was suggested that the care co-ordinator should be the “recognised authority” and be able to access other agencies as necessary. There was discussion around who the care co-ordinator is accountable to and it was suggested that he/she is accountable to the employing organisation. There was discussion around whether the care co-ordinator role is similar to that of a needs agency. It was stated that this was not the intent of the role as proposed by the strategy discussion document.

- In response to the question of how referrals would occur, referrals would be geographically based and would be in accordance with the District Health Board boundaries. Each District Health Board would have at least one local Palliative care service.

- The issue of what happens to patients who do not want to access hospice services was raised and whether they would fall through the gaps. It was suggested that there was a need to ensure that palliative care is better understood and that patients needed to get correct advice from professionals so that an informed choice could be made. It was also suggested that Hospital Palliative Care Teams would help in educating health professionals on the role of palliative care services.

- It was suggested by the Medical Director of Mary Potter Hospice that the strategy is ahead of where palliative care is presently at in New Zealand. The palliative care strategy would provide an avenue for encouraging doctors to become educated in palliative care and for palliative care to be accepted as an effective method of care.

- There were questions related to the boundaries between DSS and Personal Health, the need for longer-term care and how the Palliative Care Strategy would
solve the funding issues. It was stated that this was recognised as an issue and there would be further work in this area.

- The issue of how non-cancer patients would access palliative care services was raised and the funding issue as this could increase costs. Discussion centred on whether non-cancer patients were included in the definition of palliative care and that health professionals would need to develop guidelines for referring patients to palliative care services to ensure that they access palliative care services.

- The question was raised by Hospice New Zealand of whether there would be 100% funding for core services. It was stated that the intention of the strategy was to fully fund essential services.

- There was a general acceptance by the meeting of the strategy definition of palliative care; the vision; the development of local palliative care services and Regional Palliative Care Networks; and Hospital Palliative Care Teams.

### 3.5 Christchurch 10/8/00

**Attendees:**

Felicity Sidford (Pegasus Health); Jan Whyte (Pegasus Health); Ann Crawford (Christchurch Hospital); Kate Grundy (Christchurch Hospital); Anne Morgan (Christchurch Hospital); Margaret Hakey (Nurse Maude Association); Shona Lawson (Nurse Maude Association); Vicki Telford (Fairhaven Palliative Care Unit); Fran Puciliauslu (Wesley Care); Liz Cochrane (Amberley Medical Centre); Diana Gunn (Nurse Maude Hospice); Mardine Iggo (Nurse Maude Association); Julia Holyoake (Nurse Maude Association); Marie Glenys (Nurse Maude Association); Anna Hutt (Christchurch Hospital); Catherine Hughes (University of Canterbury); Kate Grundy (Christchurch Hospital); Colleen Walker (S C Hospice); John Doggett (S C Hospice); Liz Horn (Cancer Society); Neroli Iles (Nurse Maude Association); Caroline Gartwright (NZ Nurses Organisation) Susanne Trim; Kate Reid (Hospice Education Trust); Daphne Crampton; A Macleod (Nurse Maude Association) Deborah Woodley (Ministry of Health) Sarah Zino and Jill Nuthall (Health Funding Authority).

**Key Issues:**

- There were several questions related to referral of patients to palliative care services. These were around the need for a gate keeper e.g. GP as it was argued that open access might mean that those who really need palliative care services may not get it. It was argued, however, that the GP might have difficulty on deciding when to transfer patients, that the estimation of survival was difficult.

- There were issues around the availability of services for younger people (under sixty) and what type of services were available to them. There was a feeling that the number of younger people with terminal diseases was increasing. Sometimes younger people have to remain in hospital because there is nowhere for them to go and they do not fit the DSS age definition criteria. Resthomes were not the most appropriate place for them to go and there was a need for specialised longer-term care. It was suggested that a number of private hospitals could be
identified who could specialise in providing longer term palliative care to younger people.

- It was suggested that day hospitals could be good for people whose partner is working. If they were seriously ill then they could be in the day hospital during the day and go home to their own bed at night. It was suggested that this was a concept, which is working in Britain, but it would need funding.

- The issue of what is being done for Māori and Pacific Island people in terms of palliative care services was raised. It was noted that there are more Māori and Pacific Island people in the North Island and that it was important to consider different population groupings in each area.

- There is a need to consider the needs of dying people without a family.

- There were a number of issues raised related to funding:
  - With DSS funding if people don’t have an age related condition they have difficulty accessing DSS support services and long term care.
  - There was a need to ensure that the palliative care services were available for more than terminal patients. It was suggested however, that the resources to provide care for these people were currently insufficient.
  - It was suggested that it was important to have funding available for the education of providers, particularly for care co-ordinators.
  - More funding was needed to ensure the strategy is implemented. Services like night carer relief needed to be included in the funding. There was a discrepancy between this and DSS funding.
  - The issue of income testing was raised. There were problems for middle income people in their 30s and 40s who are heavily mortgaged, who have to drop an income and are not eligible for high user cards. It was recommended that the cost of continence supplies, drugs and equipment was paid for by the state for this group.
  - There was a need to consider additional funding for palliative care services if the services are to be open to people with non malignant diseases.
  - There was a need to consider regional equity in terms of funding.
  - The issue of whether economies of scale would be applied in funding was raised. For example, would Auckland, with a large population, be able to provide services cheaper.
  - The issue of how contracting would work with the move to District Health Boards was raised.

- It was suggested that Regional Palliative Care Services needed to be linked to more services than Oncology Centres and that linking to Oncology Centres would be too narrow. It is important that palliative care services are available for people with non-malignant diseases. It is also important to consider how rural places would figure in the development of regional services.
• There were two issues raised in relation to the role of the care co-ordinator:
  ➢ It was suggested that a General Practitioner is the best person to be the care co-ordinator.
  ➢ A rural district nurse stated that she co-ordinated palliative care for patients in her area and the Trust provided additional funding for palliative care services.

• There were several issues raised around quality and training:
  ➢ There was a need to ensure that providers did not have to meet multiple quality standards. Only one set of standards should be implemented and should not be overly prescriptive.
  ➢ Volunteers were an important part of the workforce but it was important that having volunteers did not mean that there was “skimping” on professional staff.
  ➢ The issue of using untrained staff in the rural areas for night sitting was raised.
  ➢ It was stated that there was a need for different ethnic groups to train in palliative care. There was also a need for all palliative care training to be available for all health professionals.

• It was suggested that although palliative care is a difficult area it was important to keep up the momentum in terms of the future development of palliative care services.

3.6 Central Otago

Attendees:
Joanne Tuare (Central Otago Health Services), Ann Ibbotsen (Council of Social Services), Dian Craig (Otago Daily Times); Laura Lambie and Paul Martin (Health Funding Authority)

Key Issues:
• Palliative Care Services are mainly provided by Dunstan Hospital in the Alexandra area. The district nursing service at Dunstan Hospital cares for people in the community who are dying. The Cancer Society assists the district nursing service with carer support at home.

• It was argued that while Dunstan Hospital has most of the services that are needed to care for dying people there was a need to provide a co-ordinated approach to palliative care services in Dunstan but additional funding would be required to employ care co-ordinators. Previously Dunstan Hospital had a co-ordinator service but two and half years ago funding was disestablished by Otago Hospital.
• There are concerns that people in the Central Otago region would have to rely on services in Otago which they consider too far away for reasonable access to services. There were also concerns that additional funding for palliative care services would be “swallowed up” by Otago Hospice. It was considered really important to have a palliative care service in Central Otago which would build upon the existing services at Dunstan Hospital. It was suggested that outreach clinics from Otago Hospice would also be useful.

• There was a concern that people in the Central Otago area did not know enough about the services which Dunstan Hospital provides and that six months ago a person wanting to set up a new palliative care service gave the impression that Dunstan Hospital provided a low level of palliative care services which they do not consider to be the case. It was argued by those at the meeting that any new funding for palliative care services in the Central Otago area should go to Dunstan Hospital and not a new palliative care service.

• The development of local palliative care services as proposed by the strategy was supported by those at the meeting who felt that it would work in the Central Otago area.

• The issue of funding for longer term palliative care services for people under sixty-five was raised.

3.7 Otago

Attendees:
Dave Ryan (Otago Community Hospice), Tim Carey-Smith (Otago Community Hospice), Elaine Chisnall (Health Care Otago), Elaine McFelin (Central Trust), Sharon Shaw (Cancer Society), Sue Johnston (Otago Community Hospice), Joan Carter (Health Care Otago), Sharon Dickel (Otago Hospital), Brenden Ray (Health Care Otago), Charlotte Paul (Consumer), Mark Hettan (Otago Hospital), David Holdaway (Oamaru Rural Trust), Suzanne Russel (Southland Hospice) Merren McKay (Southland Hospice) Laura Lambie, Paul Martin and Elizabeth Beresford (Health Funding Authority).

Key Issues:
• Those at the meeting thought that the palliative care strategy framework could work in the Otago region.

• A number of people raised the issue of the twenty eight day carer relief in Otago. It was felt that this needed to be reviewed as it was often not enough for dying people and it meant that people might not have the support services they needed early enough. It was also argued that there was a need to educate physicians on the 28 day carer relief scheme.
The issue of how we define palliative care was discussed and how some people require palliative care for longer than a year. It was argued that hospices could not provide care for longer than a year, nor could they provide longer-term care for patients who cannot be cared for at home.

The issue of the difficulty of providing suitable care for younger people with terminal cancer who are in their 20s, 30s, 40s or 50s was raised.

A person who has a husband with multiple sclerosis told the meeting that hospice care was not available to her husband who it was argued would “live too long” for hospice care. She argued that for people with neurological diseases who are under sixty five there are very few services available and there was a need to think about their needs as they often needed seven to eight years of long term care. Another person suggested that there was a need to have another review to look at the seriously physically disabled, and that there were not enough beds for these people. The closure of small hospitals had had a back effect on this. There is a need to determine the number of residential beds that are required.

It was argued that funding for longer term care at Health Care Otago was “nowhere near sufficient” for the patients who require this care and that more funding was required.

There were a number of issues raised related to the role of the General Practitioner in palliative care by a General Practitioner:

- General Practitioners were not funded for palliative care services and there was a reliance on the General Practitioner’s goodwill to provide palliative care services. They were central to providing continuity of care and knew the patients for a long time and were keen to continue caring for their patients when they were dying. Funding for General Practitioner services was only available through Southlink Health but it was argued that this type of service needed to be set up nationally.

- Local Palliative Care Services could administer the funding for GPs.

One person argued that the General Practitioner might not perceive the need for patients to have palliative care beyond GP care.

There were a number of issues raised in relation to the role of the care co-ordinator:

- There is a need to have a range of organisations that employ the care co-ordinator, as the person who does not want to be cared for by a hospice would be denied the service.

- Southland already provide the care co-ordinator role and it works really well there as long as the person is a good communicator.

- It would be important for the person to have an early referral to get the early benefit of the palliative care service.

There were a number of issues raised in relation to quality of care. One person stated that hospitals don’t always have the palliative care expertise for dying patients. Another person pointed out that the funder needs to have some measures of outputs.
• It was pointed out that dying people are a diverse group of people who have varying intensities of care and it was important to take this into consideration when planning for palliative care services.

• There were concerns about the proposed regional services. Southland was concerned that their local services would be diminished if there was a regional service. A person from Health Care Otago thought that there could be one regional service but several sites. It was suggested that there could be better links to North and Central Otago.

• It was raised by one person that hospitals had a number of dying people who had an aversion to hospices. Also, that some severe clinical conditions, for example, people with leukaemia prefer to die in a hospital because they have relationships with the hospital staff.

• There were a number of issues raised which were related to funding:
  ➢ GPs are not funded to provide palliative care, but do provide it.
  ➢ There is a need for more funding than $3million.
  ➢ Funding for palliative care needs to be on a population basis.
  ➢ Medications were often very costly and the high cost medications need to be subsidised.

• It was suggested by one person that people should not be able to self refer and that referral should be carried out by the General Practitioner. Several people argued against this as the GP does not always refer to a palliative care service, preferring to continue the care even if the patient needs hospice type care.

• Issues around assistance from Work and Income New Zealand were raised. It was suggested that there was a need for child support particularly for mothers with children who have chronic diseases. It was argued that there was a need for more financial assistance for people with cancer. It was argued that Work and Income was not sensitive to the needs of people with terminal disease. There was a need for agencies to work together to sort this out. A model for this was the Otago Youth Wellness Trust.

• The importance of training doctors in palliative care was emphasised as a lot of doctors had “hang ups” on drugs like morphine which were addictive.

• It was important that dying people had early access to information on palliative care.

• It was important to consider palliative care in the rural areas in North and Central Otago.

• It was important to have local palliative care services available to people in each locality.

3.8 Summary of issues arising from Public Meetings

• In all public meetings there was discussion about the need for additional funding for palliative care. GPs at meetings thought that they should be included in the funding for palliative care.
• General Practitioners at meetings thought that the role of the GP should have had more recognition in the strategy discussion document.

• There was general support for the role of the care co-ordinator. General Practitioners at meetings thought that this was a role for GPs. However, others at public meetings argued that the GP is too busy to undertake the busy role of care co-ordinator.

• The need to consider palliative care in rural areas was addressed at most meetings.

• The role of regional palliative care services was discussed extensively at all meetings and the role of the future DHBs. Many wanted to know how Regional Palliative Care Centres would work. While some meetings supported having a “Regional Centre of Excellence” most at the public meetings were concerned that regional services should not be developed at the expense of local palliative care services which they considered to be the most important.

• There was discussion at most meetings on the DSS and personal health boundary and the difficulties for people who are dying accessing DSS support services if they do not fit with the DSS definition. There was particular concern over access to longer-term beds particularly for people under sixty-five.

• There was also discussion at a number of meetings on the need to make income support more available on a needs basis.

• It was important to consider the palliative care needs of:
  - people under 65
  - those who do not have cancer and those who have a longer time before death, for example those with multiple sclerosis, particularly in relation to home support and longer term care.

• The need for education of the public and training of providers in palliative care was discussed at most meetings.
4. Focus group meetings

4.1 Māori focus group meeting: Keri Keri (Bay of Islands) 10/8/00

Attendees:
Margaret Hati, Elizabeth Hancy, Astor Toia Parkinson, May Hati, Suzanne Broacx (Hospice Bay of Islands) Laura Lambie and Louisa Ryan (Health Funding Authority).

Key Issues:
- There is a need for better and more honest information to be given at the time of diagnosis and at different stages of a person’s disease, so that the person and their family know exactly what the prognosis is and the likely time available to them to death.
- Services are not well co-ordinated between the different providers particularly the district nursing service and the Māori provider service.
- Nurses only being available from 9am-5pm was a problem. It was suggested that there was a need to have nurses more readily available as the demands of managing children, the dying person and the whānau are very great.
- The group supported the idea of having a Māori care co-ordinator. A person like this would have been able to help the carer to access services. They would also be able to help the carer inform the “wider whānau” of the appropriate visiting time as he/she is often overwhelmed with visitors and having to care for the dying person.
- There is a need for a linen service particularly in the Far North as it is often raining and in dry periods there may be insufficient water as the well may be low.
- There is a need for counselling services for the carer and for the children. The children are often left out. This could be linked with the school counselling service.
- The group suggested that a public Hui about “care of the dying” would be useful. They also suggested that a video presentation could be useful to discuss at the Hui. This video would be specifically directed at Māori and include factors such as the problems that occur after the death of the person.
4.2 Māori Focus Group Meeting: Porirua 29/8/00

Attendees:
Coleen Wineers (Capital Coast Health), Renei Hill (Capital Coast Health), Charlene Williams (Te Runanga O Toa Rangitira – Ora Toa Health Unit); Laura Lambie and Sue McTavish (Health Funding Authority).

Key Issues:

- The group indicated that the word “palliative” is not really understood by Māori.

- It was stated that in mainstream services the focus is on the individual but for Māori it is on the whānau. The group recognised that hospice care is more acceptable than hospital care as it is value based and includes the spiritual dimension.

- It is important that there is better co-ordination between mainstream providers and Māori providers; currently there is too much competition to the detriment of Māori. Also, there are too many health professionals going into the home of the dying person. On the other hand, the group stated that it was their perception there was a reduction in community services e.g. District Nursing Services.

- Families are not always made aware of entitlements to practical and other support at the time of discharge from hospital.

- It was suggested that Marae-based palliative care services are needed as Māori need familiar faces and familiar surroundings and many prefer a Māori worker. The group indicated that older Māori are often reluctant to ask for information and a Māori provider could facilitate this. A Marae-based pilot was recommended. The group suggested that if the funding stays with existing providers then this limits the ability of Māori providers to gain contracts in palliative care.

- The group stated that palliative care to Māori involves care from the whānau and in the main does not require a high level of skill. This requires a partnership between the Māori provider and the hospice to provide care co-ordination with essential skills being taught to the family e.g. lifting. The control needs to sit with the family and patient and not with the health professional.

- It was suggested that the Māori care co-ordinator should be employed by a Māori provider and have good links to regional and local services. The Māori care co-ordinator should not be under the control of a mono-cultural organisation if care co-ordination is to work for Māori. The Māori provider needs to know a position is available before they will encourage a person to train.

- The group indicated that more Māori people need to be trained in palliative care.
4.3 Pacific Island People: focus group meeting, Auckland 29/9/00

Attendees:
Susana Hukui (Consumer), Denise Kivell (Kidz First Home Care), Fuafiva Faalae (Researcher Pacific Health Research Centre), Meia Schmid-Ulli (Paediatrician), Graeme Kidd (South Auckland Hospice), Alec Ekeroma (Pacific Medical Association), Metua Faasisila (Starship Hospital), Ben Taufua (South Auckland Health), Niusulu Charlton (Auckland Hospital), Linola Kowamatangi (Auckland Hospice), Karenina Siaosi Sumeo (Auckland Hospital).

Key Issues:
This meeting was run by the Pacifica Medica Association. A presentation on the strategy was given at the beginning and the ex-president of the Pacifica Medica Association chaired the meeting.

- A Pacific Island paediatrician was asked to outline the issues for Pacific people in terms of care of the dying which were:
  - Pacific people prefer caring for their own dying family members at home and moving family members into another setting is not always acceptable
  - death for Pacific people is seen as God's will
  - palliative care needs to be accessible and affordable for Pacific people
  - barriers to access to palliative care include lack of information on what is available and the communication barrier of having a different language
  - there is a need to consider the “Pacific competence” of mainstream providers in hospitals and hospices
  - it is important to include the spiritual aspects of care for Pacific people
  - there is a need for more research into Pacific people’s needs in relation to care for the dying
  - a Pacific Palliative Care Team, which includes a key worker, was suggested
  - there is a need for appropriate respite care for Pacific people
  - there is a need for trained Pacific Island nurses and doctors.

- A General Practitioner from South Auckland Hospice responded to these issues by providing some information on what the hospice offers and how it has met the needs of Pacific people as follows:
  - it was stated that the hospice has tried to attract Māori and Pacific health professionals but had not succeeded
  - it was pointed out that the proportion of Pacific people using the hospice was similar to the proportion of the Pacific population in the South Auckland area
the hospice is a place of respite and caters for all cultures; it caters for 500 referrals a year, is a community service, has 400 volunteers and has raised $5 million dollars for the building of the hospice.

the focus of the hospice was on caring for families and the hospice has a whānau room and 90% of people cared for die at home.

- A Pacific woman whose husband died four months ago outlined her experience of the care provided for her husband:
  - Her husband had 27 days of care by South Auckland Hospice which provided a palliative care nurse who was the point of contact with the hospice and also linked them to the services they required. This was an excellent service which provided a lifeline to the family. She stated that while it would have been nice to have a Pacific person at the hospice it did not matter that the person providing the care was not a Pacific person. The important thing was having someone to provide help when needed especially clinical help including help with medications. She thought that other Pacific people needed to be able to access this service.
  - She stated that the care her husband had had in hospital was not as good. They gave her husband too much medication (which he did not want) and the hospital did not cater well for the Pacific family and visitors.

- People were asked the question of what were Pacific people’s needs in terms of palliative care.
  - A Pacific social worker expressed surprise that Pacific people used the hospice but still thought that there was a need to recruit Pacific health professionals into hospices. Language was the biggest barrier to accessing palliative care services. She stated that there should not be an expectation that carers should administer drugs and that some Pacific people prefer clinical people to do this. There was a need for more promotion of hospice services to Pacific people.
  - Another social worker thought that counselling was very important as was support for the carer and the family after the death of the family member. She also felt that there was a lack of awareness among Pacific people of the palliative care services that were available. Few of her patients went to a hospice and tended to use the district nursing service.
  - A children’s nurse indicated that palliative care services for children were good at Auckland Hospital but non-existent at Middlemore Hospital.
  - A person from the family support unit at Starship Hospital stated that there were often problems for Pacific people who are non-residents. Usually the family and community assisted these families but it could be a problem if they have to pay for care. She suggested that there was a need for a Pacific Philanthropic trust to help non-resident Pacific people.

She also suggested that the care of Pacific children and adults was the same in terms of the support requirements. The differences were in the clinical needs. There was a need for a Hospital Palliative Care Team for children - Starship operates an excellent team.

There was also a need to consider income support on a more needs basis to enable Pacific families to care for their children at home.
Hospital staff needed to understand the Pacific cultures when caring for Pacific people, for example, following a child’s leg amputation the support unit told the laboratory staff to preserve the leg until the child’s death so that the leg could be buried with the child in accordance with the Pacific culture.

- The General Practitioner at the meeting stated that the important thing for Pacific people was to use the palliative care services that are currently available and there was a need to empower Pacific families to use these services. It was important to ensure that they knew what palliative care services were available.

- An Obstetric and Gynaecology specialist talked about how he cares for gynaecology patients with cancer. He indicated that doctors had not had training in counselling cancer patients and had to really train themselves. He was pleased to hear of the services that were available.

- There was discussion on the importance of having a Pacific family member available when the person was being told about cancer and their prognosis.

4.4 Carer Focus group: Dunedin 15/8/00

Attendees:
Marion Sinclair, Jack South, Jo Scott, Colleen Ischia, Margaret Pirrett, Tom Winter, Bev Abernethy, Graeme Dunn, Susan Joka, Sue Johnstone, Eri Bennett.

Key Issues:

- The term “Palliative Care” was not well understood by the group.
- The majority of the group agreed that the hospital was not really an appropriate place for dying people and that a hospice was a far more acceptable place. They liked the family atmosphere and the lack of a clinical environment. There was a concern about what happened when both the hospice and hospital are full.
- One person stated that there needs to be a dietician attached to the hospice to provide advice to carers on the preparation of suitable meals. This was supported by the group.
- It was one person’s experience that her General Practitioner was scared to prescribe strong pain relieving drugs like morphine. Others agreed that this was a problem while others thought their General Practitioner was great.
- Some members of the group had difficulty accessing district nurses. They would contact them and they would not return their calls until the next day. Others thought that the district nurses were very good and were readily available to them.
• People who had used day care at the hospice found it very useful. One person indicated that it was a “real lifeline” and it helped to build the relationship with the family.

• People who had used night nursing services found this to be a great relief for the family. There was a concern that the 28 day relief package which covers both night nursing and respite care was not sufficient for some people. One person “ran out of carer relief” which was a real problem for the family. They eventually persuaded the Cancer Society to provide additional night carer relief.

• The issue of counselling was discussed. Most of the group felt that there was a need to have someone independent to talk to. Some felt the word “counselling” was inappropriate and that “support” would be more appropriate. The issue of children’s counselling was discussed. It was suggested that we “forget” about the children yet they are very traumatised with the death of a parent. One woman tried to access Canteen grief workshops for her children but was not successful. This woman did, however, have a lot of support from the Child Cancer group.

• The issue of rest homes was discussed. The view was that they generally didn’t seem to know much about palliative care and that the level of care was too low for people requiring palliative care. They thought that this may be due to a lack of training and the numbers of registered nurses in rest homes. A person whose mother was under sixty said that rest homes were not really set up for younger people and for palliative care. She suggested that rest homes should be accredited to provide palliative care.

• The total group supported the introduction of care co-ordination. The group all agreed that a care co-ordinator could help them access the services they needed:
  ➢ One woman said she spent a lot of time on the phone trying to find out what was available. Another thought that the care co-ordinator could assist with accessing benefits through Work and Income New Zealand.
  ➢ About half of the group indicated they had problems accessing essential equipment. One woman needed a hospital bed but had trouble finding a District Nurse who knew what was available. Approval for modifications of a bath came after the death of a carers husband. Another who required linen only got linen when she also got a hospital bed.
  ➢ There were a few carers who stated that they were given all the equipment they needed.
  ➢ One woman said her husband did not have sufficient pain relief and a care co-ordinator would have very useful for helping her to get this sorted out. This woman said that the GP and the Palliative Care Medicine specialist were not working together to manage the pain. She went through four doctors in one day.
  ➢ All thought that if there was going to be a care co-ordination service then there needs to be sufficient care co-ordinators.

• The group thought that there needed to be consideration given to providing palliative care in rural places.
### 4.5 General Practitioner Focus Group 27/9/00

**Attendees:**

Tim Carey-Smith, South Link Health; Graeme Kidd, South Auckland Hospice; Willie Landman, South Auckland Hospice; Phil Jacobs, Pegasus (teleconference); Laura Lambie, HFA; Deborah Woodley, MoH.

**Key Issues:**

In general, there was support for the definition, principles, vision, and essential services. Points raised with regard to these areas were:

- The palliative approach is integral to all general practice.
- Inclusion of a timeframe within the definition: there was disagreement over whether the inclusion of a timeframe would be appropriate - it was agreed that we needed to ensure inclusion and not exclusion of people. A timeframe might exclude people with non-malignant disease. However the absence of a timeframe might leave things too open-ended and could have flow-on effects with regard to funding.
- There is a real need for education of both the public and clinicians in palliative care.
- There is a need for good information flows - GPs sometimes have difficulty in keeping informed of patient status in terms of what care their patients are receiving and their condition – GPs can easily get out of the loop in terms of the provision of care to dying people.
- Support services were seen as essential. There was recognition that there are current funding problem, education/awareness issues, and placement options. Standard setting is a better way to go than nominating particular rest homes i.e. the broader the base, the better the access and care.
- There should be specification of what is the minimal requirement for a multi-disciplinary team e.g. PC physician, GP, nursing support, counsellor; and at a maximum the team could also include a social worker, pharmacist, dietician, physiotherapist, OT, spiritual worker, cancer society representative and additional nursing roles (e.g. palliative care nurse, district nurse, oncology nurse etc.)

The key issues of concern were:

- The diagrammatic and proposed link to oncology services was not seen as appropriate especially in a strategy that is for all conditions not just cancer. The linkage to oncology proposes a medical model which is not always consistent with delivery of good palliative care.
- The proposed regional structure - development at a local level is important. Linkages need to be made (and are made now) nationally. The advantage of regional centres was not seen. The structure should be flexible as it is difficult to apply one structure to the whole country.
- The co-ordinator role is currently being done by general practice - it would be confusing to put in another person/layer. There was no agreement over putting in
a nurse specialist into this role. It was felt this person could “take over”. They would prefer a “liaison” person/facilitator. In addition care co-ordination could be seen as a function rather than being carried out by a particular person. It is also important to retain a multidisciplinary team approach.

- It was suggested that palliative care provision at a GP level is a loss maker and that funding provision should be made for General Practitioners.
- All hospitals should have palliative care expertise not just the tertiary facilities. The palliative presence in hospitals could form a good linkage with GPs.
- Above all there needs to be a greater recognition of the role of general practice in palliative care. Alternative diagrams were suggested.
4.6 Summary of issues from focus group meetings

Māori focus group meetings
There is a need for:

- More information around the time of diagnosis with regard to the prognosis and time to death. There is a need for a public Hui on the care of the dying for Māori and the development of a video for Māori.
- Mainstream services need to understand the role of the whānau in caring for dying family members.
- More services should be available on a 24 hour basis and there should be better co-ordination of services particularly between mainstream and Māori providers.
- There needs to be Counselling for carers and children.
- Marae-based palliative care services and a pilot was suggested.
- Training in palliative care for Māori providers is needed.

Pacific people focus group:
- Pacific people prefer to care for their dying family members at home.
- There is a need for palliative care services to understand Pacific cultures especially in terms of the dying.
- It is preferable to have a Pacific health professional providing palliative care services, but they are difficult to recruit. There is a need for more training of Pacific health professionals in palliative care.
- The hospice philosophy is consistent with the Pacific philosophy of dying and hospices can provide care to Pacific people in a “culturally safe way”.
- There is a need for more information to be disseminated to Pacific people on what palliative care services are available.
- There is a need to consider the specific needs of children within the context of the Pacific family.
- There is a need for hospitals to better understand Pacific cultures and when to introduce/refer people to palliative care services.
- There was a need to consider the support and financial needs of non-resident Pacific people with family members who are dying.

The Carer focus group:
- The Hospice is more acceptable than the hospital to provide care for the dying.
- Day care was really helpful for dying people and their families.
- There is a need to:
- ensure access to nursing services on a 24 hour basis
- educate General Practitioners on palliative care particularly in prescribing pain relief
- make carer relief available on a needs basis
- ensure that counselling is available for children as well as for adults
- ensure that there is suitable long term palliative care available particularly for people under 65.

**General Practitioner focus group:**

There was:

- General support for the definition, principles, vision and essential services.
- Agreement that much of the role of the care co-ordinator was undertaken by the General Practitioner. There was a need to make care co-ordination a function rather than being carried out by a particular person.
- Disagreement over the usefulness of regional services. The development of local services is important. A national structure should oversee the quality and education of palliative care providers.
- support for greater recognition of the role and funding of general practice in palliative care.