
IN THE HIGH COURT OF NEW ZEALAND
WELLINGTON REGISTRY

CIV-2015-485-235

UNDER	**The Declaratory Judgments Act 1908 and the New Zealand Bill of Rights Act 1990**
BETWEEN	**LECRETIA SEALES**
	Plaintiff
AND	**ATTORNEY-GENERAL**
	Defendant

AFFIDAVIT OF DR SINÉAD DONNELLY ON BEHALF OF THE DEFENDANT

12 **May 2015**

Judicial Officer: Justice Collins
Next Event Date: Hearing commencing 25 May 2015

CROWN LAW
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I, Sinéad Maire Donnelly, of Wellington, physician, swear:

Qualifications and experience

1. I am a medical doctor trained as a physician through Royal College Physicians Ireland and specialising in palliative medicine. I am a fellow of the Royal College of Physicians of Ireland and Fellow of the Australasian Chapter of Palliative Medicine.

2. I began my specialist training in Ireland at Our Lady's Hospice Dublin, the second oldest hospice in the world established in 1879 (the oldest being St Patrick's Hospital, Cork (1870)).

3. I completed my postgraduate Doctorate in Medicine under Professor Declan Walsh, Professor of Palliative Medicine at the Cleveland Clinic Foundation, Ohio, USA researching the quality of life and symptom assessment in 1,000 patients with advanced cancer. Professor Walsh's unit was a World Health Organisation (WHO) demonstration project in palliative care, at that time leading the development of palliative medicine in the USA.

4. I continued my specialist training under Professor John Welsh, Professor of Palliative Medicine at Glasgow University, Scotland. I subsequently took up a position as the first specialist in palliative medicine in mid-west Ireland leading the development of a high quality integrated palliative medicine practice serving a population of 350,000 people in the hospital, specialist palliative care unit and community. For 24 years I have been involved in the care of over 400 people each year who have advanced progressive illnesses and die.

5. I have been practicing in New Zealand since 2008, up until 2013 in the palliative care service at Wellington Regional Hospital, and spent a period with Te Omanga Hospice. I currently work as a general medicine physician at Wellington Regional Hospital, integrating my specialty area of palliative medicine into acute hospital practice. Hospital is the location where the majority of people die thus an important area in which to maximise standards of palliative medicine

6. I am the palliative medicine module convener for the Otago School of Medicine in Wellington. In that role I am responsible for teaching and co-

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ordinating the teaching and assessment of 4th and 5th year medical students in relation to palliative medicine.

7. I am also actively involved in research in the area of palliative medicine. I have a number of publications in this area, and I have recently published a paper in International Quarterly Journal of Medicine on Relatives' and Staffs' experience of patients dying in ICU. I am reviewer for the New Zealand Medical Journal.

8. A copy of my CV is attached as exhibit **"SMD-1"**.

9. I have been on the New Zealand executive of the Australian and New Zealand Society of Palliative Medicine (ANZSPM), and a member of the Australasian council for 4 years. I was the Deputy Chair of the New Zealand section from 2010 to 2012, and Chair from 2012 to 2014.

10. I represent the palliative care doctors of New Zealand on the Palliative Care Council of New Zealand. The Palliative Care Council is a ministerial advisory committee established in 2008 under s 11 of the New Zealand Public Health and Disability Act 2000. It is an independent body with a multi-disciplinary membership. The Council's role is to provide independent and expert advice to the Minister of Health, and to report on New Zealand's performance in providing palliative and end-of-life care.

11. I confirm I have read and understood the Code of Conduct for Expert Witnesses and I agree to comply with it. Further, I confirm any opinions I express in this affidavit are within my areas of expertise and experience.

12. In this affidavit I explain the harm that legalising physician assisted suicide and euthanasia will do to the practice of palliative care in New Zealand and to the future development of palliative care services in New Zealand. I also explain that in addition to compromising palliative care for others in the future, Ms Seales' orders, if granted, will place other vulnerable people at direct risk of harm.

13. I also address what I understand to be Ms Seales' allegation that living with a life limiting illness in New Zealand with the support of quality palliative care services amounts to 'cruel and inhuman' treatment. I describe how a palliative

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care team would endeavour to care for any patient with a constellation of symptoms and needs similar to Ms Seales.

Palliative care in New Zealand

14. I have read the evidence of Dr Roderick MacLeod. I am in general agreement with it and wish to add the following points.

15. The Ministry of Health published the New Zealand Palliative Care Strategy in 2001. A copy is annexed as exhibit **"SMD-2"**. A working definition of palliative care in New Zealand was published in 2007, just prior to the formation of the Palliative Care Council. This is attached as exhibit **"SMD-3"**.

16. The New Zealand working definition of palliative care adopts the 2002 WHO definition as its starting point. This definition emphasises that the focus of palliative care is on life, not death. It is about affirming and improving the quality of life up to the time of death.

17. The WHO definition of palliative care for adults provides:

> Palliative care is 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 early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:
>
> - Provides relief from pain and other distressing symptoms
> - Affirms life and regards dying as a normal process
> - Intends neither to hasten nor postpone death
> - Integrates the psychological and spiritual aspects of patients' care
> - Offers a support system to help patients live as actively as possible until death
> - Offers a support system to help the family cope during the patient's illness and in their own bereavement
> - Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
> - Will enhance quality of life, and may also positively influence the course of illness
> - Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

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18. The New Zealand working definition discussion paper records that New Zealand needs to take into account a number of factors particular to our context, including the fundamental place of the Treaty of Waitangi, and the cultural diversity in New Zealand. The paper describes these:

> The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau (family health).
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> . . .
>
> Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whanau in contemporary New Zealand society.

19. Based on those and other factors, the working definition of palliative care in New Zealand is set out as follows:

> Care for people of all ages with a life-limiting illness which aims to:
>
> 1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
>
> 2. Support the individual's family, whanau, and other caregivers where needed, through the illness and after death.
>
> Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.
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> It should be available wherever the person may be.
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> It should be provided by all heath care professionals, supported where necessary, by specialist palliative care services.
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> Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. These include Maori, children and young people, immigrants, refugees, and those in isolated communities.

20. New Zealand has a standard of palliative care that is one of the best in the world. I agree with Dr Roderick MacLeod that there are challenges and room for improvement, particularly in the accessibility and delivery of quality palliative care services beyond the hospice framework. One of my key interests, and that of the hospital palliative care team in Wellington Regional Hospital, is to improve the integration of palliative care into the general hospital framework. Others, including Hospice New Zealand, are working to

improve palliative care services in the primary care setting, and in aged care facilities. The goal is to have a seamless service wherever the patient is, collaborating to provide holistic, highly individualised care between primary health providers, hospitals and hospices. These steps are essential to ensure that all New Zealanders can access high quality palliative care. Progress is being made but there is still much to be done.

21. A person in Ms Seales' position would be able to access some of the best palliative care services available. These services do not allow a 'cruel or inhuman' death. Nor do our patients live their lives or die without dignity. In my 24 years of practice I have never seen an undignified death.

22. Palliative care services in New Zealand are holistic, with high aspirations of care and support addressing the physical, social, emotional and existential needs of the person and their whanau. It takes a multi-disciplinary approach involving not just doctors and nurses, but also physiotherapists, occupational therapists, dieticians, pharmacists, volunteer visitors, art and music therapists, social workers, chaplains, and so on. It is not a bleak desperate reality. We focus on living fully in the moment while preparing realistically for the person's unavoidable death. We use all our resources to maximise independence and achieve the patient's goals for living while still holding in careful balance the reality that this person will die. We explore carefully with the person who is facing their dying how much they wish to discuss. We move at their own pace. A patient may choose to explore these very personal and deep issues with any person on the multidisciplinary team or their family or their GP. In palliative care we create a space where this can happen. The concept of palliative care is to provide a cloak or a shield, acknowledging that their illness cannot be taken away, but cloaking the person and their whanau in care.

23. The basic principles of palliative care do not change depending on whether the person has their full mental faculties or not. There are always the same issues to address but how we do that changes with each person. How we care for a person with dementia, for example, may be different: it may be no use talking, but we can hold their hand and console them by our care, always respecting their full humanity as a person, even if they can't remember themselves.

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24. I wish to emphasise this point from the WHO definition of Palliative Care, as it is relevant to patients such as Ms Seales, that input from palliative medicine and palliative care "Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications."

25. It is also recognised that referral to palliative care, especially if made early in the process before issues become acute, can not only improve the quality of a person's life, but also help them live longer. This is not surprising: as their symptoms (such as pain and nausea) are relieved people may eat more, move around more, take more enjoyment from their days. This means that not only do they experience less distress they avoid unnecessary complications such as infections and pneumonia.

26. I understand that an argument has been made for euthanasia and assisted suicide on the basis that gives people a sense of control and autonomy, because it allows them to discuss death and the options available so they feel they have a choice of what they are able to do. My response is that keeping the patient central to our care is fundamental to good palliative care. The bedrock to achieve this is our skill in listening, attending and communicating. We endeavour to provide maximum autonomy for living, to enable the patient to live fully until they die and to die naturally. People maintain their dignity although becoming more disabled. Dignity is imparted in the way we provide care.

Specific aspects of palliative care in New Zealand

27. Palliative care services in New Zealand are very good at relieving and ameliorating pain, and intractable pain is extremely rare.

28. Our experience is that people's perception of pain will be impacted by emotional, social, physical and existential features. How we care for a patient in pain can therefore be quite complicated.

29. For example, if someone's pain is purely physical, and all other factors are perfectly aligned, we would be able to use medication and non-medication modalities. Some types of pain respond well to radiotherapy. Nerve pain is more complex and needs a more complex response, usually with input from a

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palliative medicine specialist. Generally we can foresee when pain is going to be more complex, and patients will be referred to specialist units to spend time to work out the best management regime. More research is needed but great strides have been made in recent years as research in palliative medicine develops internationally with professorial units and academic publications.

30. Pain relief is much more than morphine which is a opioid, but even at that basic level work is being done to develop different types of effective opioids eg oxycodone, hydromorphone, methadone and fentanyl. The science of analgesia or pain relief for bone pain, nerve pain and complex pain etc is constantly evolving with new agents developed internationally being applied in New Zealand. Great strides have been made in the past 30 years as palliative medicine becomes recognised internationally as an important medical specialty in its own right. Palliative medicine specialists are trained to know how to apply all this burgeoning knowledge to the individual patient and their particular needs.

31. If pain has other aspects to it, perhaps a person has layers of unresolved issues in their lives for example, fear of dying, regret, hurt, harm or lack of forgiveness that may affect how the pain feels to them. Even though the physical pain might in another person be resolved quite easily for this person it magnifies with a high level of anxiety and fear. The physical pain can be just the tip of iceberg, and the palliative care response is to try to address the complexity of that pain through a multi-disciplinary team response. A person with such a high level of fear and anxiety might benefit from an admission to a specialist palliative care unit or hospice for perhaps a week to maximise the team's input to explore and help the patient.

32. Sometimes if the person is close to death, has been referred late to the palliative care team and there is no time to explore and address the underlying issues, the only option might be to offer them medication just to help to calm them. Sometimes if the person is extremely agitated and distressed this may reduce them to a semi-conscious state.

33. This means of symptom control is through easily reversed, short acting medication. As with all pain relief, you titrate the dose: you start the lowest dose and see how that works to settle the person's pain and distress over the

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next few hours. You constantly review and reassess what you are doing and what the optimum treatment is for the person at each stage.

34. This is not 'deep sedation'. It is a sedative medication in lay person's terms but the dose is titrated and monitored and the focus is symptom relief. It would be extremely rare for this to be used for any length of time.

35. I have never seen the practice of deeply and permanently sedating a patient until they die of starvation. Such a practice would be totally inappropriate and is not a palliative measure.

36. Lay people are sometimes confused with what happens with providing patients with fluids and food near death. For example, if we are caring for someone with advanced cancer that has spread to their liver, who has a partially blocked bowel and can't keep down any food, there is a question as to whether they should be put on a drip or maybe consider surgery. You always have to think about the risks and the benefits, the reversibility of the underlying illness, the patient's comfort and the reasonableness of an intervention. So for this person who is dying in the near future we might discuss surgery or a stent if it would improve the quality of their life. If we can't overcome the block we continue to discuss with the patient and their family how we can keep them comfortable with excellent nursing care and relief of pain and nausea. Patients and families may ask about artificial hydration and nutrition which we will discuss, exploring benefits and risks of such interventions, as well as how long the patient is likely to live, where they wish to be cared for and by whom. So every decision small and large are made with the patient and family at the centre.

37. If someone is very undernourished and or close to dying, giving them a drip with fluids could potentially make dying worse. If their body is shutting down they won't be able to cope with the fluid, and the fluid then tends to get into their lungs, which causes distress and shortness of breath. Research has shown that the best option for comfort is excellent mouth care, and that moistening the mouth (for example with an ice block) is much better than taking fluids in by drip or drinking.

Euthanasia and assisted suicide are not part of palliative care

38. The Palliative Care Council of New Zealand issued a position statement on euthanasia in June 2013. This is annexed as exhibit **"SMD-4"**. I agree with

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this position statement. It is also consistent with the position statements of the World Medical Association, the New Zealand Medical Association, the Australasian and New Zealand Society of Palliative Medicine and the Palliative Care Nurses Society. The statement is endorsed by Cancer Control New Zealand.

39. The position statement notes that there has been widespread debate in New Zealand society about euthanasia and physician assisted suicide, largely based around anecdotal stories of sub-optimal care at the end of life.

40. The position statement records that access to quality palliative care is essential if societal fears around care at the end of life are to be allayed. It also records that dignity in dying is a fundamental goal of palliative care, and puts forward as an example *Te Wa Aroha*:

> Through work done at Starship Children's Health, Maori leadership offer us "Te Wa Aroha – Allow Natural Death". Te Wa Aroha means "a time of love" and focuses on what can and will be done at the end of life for individuals and their families, and that this time and care is as natural as possible. Terminology emphasises reducing suffering and promoting comfort, quality and dignity.

41. The position statement sets out a definition of Palliative Care in New Zealand, emphasising that it affirms life, regards dying as a normal process and intends neither to hasten nor postpone death:

> Palliative care is the care of people dying from active, progressive diseases or other conditions that are not responsive to curative treatment; providing relief from pain and other distressing symptoms. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing – tinana, whanau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care integrates a multi-disciplinary team approach to address the needs of patients and their families/whanau, extending into the psychological and spiritual aspects of care and into the bereavement phase if required. Palliative care affirms life and regards dying as a normal process and intends neither to hasten nor postpone death.

42. The position statement records that conversations about euthanasia and physician assisted suicide must focus not only on the wishes, fears and concerns of individuals but also on what is right for the community.

43. The Council states that it believes that dying is part of the experience of living and that no-one has to die in avoidable pain and suffering. All New Zealanders have the right to receive high quality palliative and end-of-life care regardless of ethnicity, age, geographic location or diagnosis. It goes on:

> When requests for euthanasia or assisted suicide arise, particular attention should be given to good symptom control, especially those commonly associated with a serious and sustained "desire for death" such as depressive disorders and poorly controlled pain. In such situations early referral to an appropriate specialist should be considered.

44. The position statement concludes with the following statements of principle:

> The Palliative Care Council
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> - *strongly encourages* the concept of death with dignity and advocates that this be a high priority for health care in New Zealand;
>
> - *acknowledges* it is not always possible to completely relieve suffering, but that good palliative care improves the experience of living with and dying of a terminal condition;
>
> - *believes* that people have the absolute right to refuse life sustaining treatments including the provision of medically assisted nutrition and/or hydration, and that carrying out the person's wishes of refusal does not constitute euthanasia;
>
> - *believes* that the benefits and harms of any treatments (including the provision of medically-assisted nutrition and/or hydration) should be considered before they are started and that the benefits and harms of continuing treatments should also be regularly reviewed. Stopping treatments that are not benefitting the patient is not euthanasia;
>
> - *believes* that if treatment appropriately titrated to relieve symptoms has a secondary and unintended consequence of hastening death that this is not euthanasia;
>
> - *advocates* that all patients should be made aware of the options for hospice and palliative care, with individual assessment of their needs to ensure appropriate palliative care is being provided;
>
> - *believes* that euthanasia and physician assisted suicide do not have a place in New Zealand society; instead the focus should be on ensuring high quality palliative care is available to all who would benefit;
>
> - *notes* that both euthanasia and assisted suicide are against the current ethical positions of the medical and nursing professions in New Zealand;
>
> - *understands* the practices of euthanasia and physician assisted suicide to be illegal in New Zealand and that palliative care does not include the practice of either as there is a clear distinction between good care for the dying and active interventions instituted in order to deliberately end the life of a patient; and
>
> - *acknowledges* that there are divergent views held by wider society about the ethics of euthanasia and physician assisted suicide and respects and upholds the rights of all to their own personal views.

45. As the position statement makes clear, respecting the rights of others to hold divergent views does not equate to agreeing that those divergent views are correct or valid, or that there is any doubt or uncertainty in the views held. The Palliative Care Council, along with the professional associations most

directly involved in the provision of palliative care in New Zealand are very clear that physician assisted suicide and euthanasia are not part of palliative care, and that allowing physician assisted suicide and euthanasia in New Zealand would be unethical and harmful. I share that view.

46. I also share the view that to invoke euthanasia and assisted suicide as a solution to concerns that end of life care may be sub-optimal is wrong, and contrary to the basic ethos of a caring community. The right response to such concerns is to ensure that the highest quality palliative care is available on an equitable basis to all New Zealanders.

47. It is my experience that prematurely ending the life of a patient is not necessary to achieve relief of their suffering. In 25 years I have never met a patient who consistently requested that I end their life. A person might say that the struggle is hard, that they wished it was over, that they have thought about the option of euthanasia. It is my experience that when each person is listened to, attended to, respected and provided dignity by the way we care and attend, such cries for help dissipate. I am not saying that this intensive care which we provide to a person is easy. It is demanding and challenging. But it is effective.

48. In caring to the best of our ability for someone who is dying we ease the grief and reduce the burden of bereavement for those left behind. It is true that people suffer physically, emotionally and psychologically with advanced illnesses, facing the existential uncertainty, anxiety, fear of dying and death. It is also true that every day the intervention of palliative care can transform such suffering and fear of future suffering by easing physical symptoms, by resolving social worries and by attending to existential and spiritual issues.

49. What is striking to me is how unique and individualised every person's journey and death is. Each person brings the layers and layers of their life experiences into their dying. With early and timely referral to a palliative care team, we endeavour piece by piece to witness, acknowledge, attend and relieve their physical, emotional, social, spiritual distress and that of their family and friends. It is work for which we as palliative care specialists, nurses, doctors, social workers, chaplains are trained. So often I am in awe of the extraordinary transformations that occur in people facing dying and death when a healing space is created of acceptance and care.

50. My firm view is that allowing a person to go through the process of a natural death is better for the patient and their family. In the process of dying there is much living to be done, and I have witnessed time and time again how much people grow through this process. This is what holds those of us who work in palliative care: we witness this growth and hope and transformation so often, and we have the privilege of helping it, and walking alongside those who make this journey. We work hard and work to increase our skills and develop the knowledge in this area because we see what huge benefits it delivers to people in this most vulnerable period of their lives.

51. We who work with the dying every day are not romanticising this process: this is what we see. Palliative care is effective. It is the appropriate and compassionate response to the needs of this group of the most vulnerable people in society.

Other voices

52. With reference back to the working definition paper, and the fundamental importance of the Treaty of Waitangi and the recognition of New Zealand's cultural diversity, I am concerned that this case seeks to make a fundamental change to how we approach end of life care:

52.1 Without consideration of the Treaty of Waitangi;

52.2 Without reference to views or interests of others with different cultural beliefs, values and practices, including refugees and immigrants;

52.3 Without consideration of the impact of this change on the practice of palliative care in New Zealand and on medical ethics;

52.4 Without consideration of the impact of this change on groups that are more vulnerable than Ms Seales' sees herself as being.

53. My evidence touches on the third of these points and the fourth in relation to people with life limiting illnesses. I am not qualified to address the first two, but as the New Zealand working definition document makes clear, these are interests that must be taken into account where there is such a significant change to how New Zealand society responds to the needs of those with life limiting illness.

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Euthanasia and assisted suicide conflicts with fundamental medical ethics

54. I have seen the evidence of Dr Landers, which sets out the position statements from the World Medical Association, the New Zealand Medical Association and the Australian and New Zealand Society of Palliative Medicine. Each association has a clear statement that euthanasia and assisted suicide are not ethical.

55. This is a core ethical principle of medicine: doctors do not kill their patients.

56. It would be immensely harmful to the practice of medicine in New Zealand for the law to separate from and seek to override such a fundamental ethical principle. It would place ethics and law in conflict, and create the position where the State endorsed doctors acting lawfully but unethically.

Euthanasia and assisted suicide conflicts with and undermines good palliative care

57. Legalising physician assisted suicide and euthanasia would compromise our ability to provide good palliative care for our patients.

58. In general terms, it would fundamentally change the relationship between doctor and patient. Doctors would be exposed to demands to act unethically. Patients would be exposed to doctors who responded to their concerns by agreeing that suicide is the best option, or even actively offering suicide as a preferable course to palliative care. Given the imbalance of power in the doctor/ patient relationship, and the particular vulnerability of those with life limiting illnesses, the message that suicide or euthanasia is the best option would have profound impact.

59. Some patients would be concerned that their doctor might act to harm them without their consent, or would be worried that doctors might not try hard enough to help them because of an expectation that they ought to opt for euthanasia.

60. We would be in a whole different world, where the trust that no matter what happens a doctor will first do no harm, is broken.

61. On a day to day basis, placing the option of euthanasia and physician assisted suicide on the table would profoundly undermine the palliative care that we deliver.

62. Many people when they first access hospice services are afraid, and one of the first things that needs to happen is to establish trust and rapport between the person and their carers. We need to provide assurance that we can help them with what they are facing, and that every day we will be there with them and work with them to deal with what they are going through. Our job is to not let the prospect of death overwhelm life, and to help people have as good a life as possible right up until death.

63. People who are afraid need to have their fears addressed: helping them commit suicide is not a compassionate response. Our experience is that when people with a life limiting illness say that that they don't want to live anymore, they mean that they don't want to live *like this*, with whatever pain, fear, or suffering that they are experiencing. Palliative care is all about identifying and alleviating whatever *this* is.

64. Sometimes the act of listening as the person tells their life story or their story of disappointment, anguish or despair as they face an unfair and untimely death is all that is needed to provide relief. It is difficult to describe in words, to communicate on paper what we achieve in palliative care. It has to be experienced as a patient, as a family/whanau, as a palliative medicine doctor, as a palliative care nurse etc to fully understand. Recognising that cure is not possible, raging perhaps against the unfairness if life and experiencing the agony of leaving the people you love, healing can occur and life can be lived fully in each moment. The focus shifts and the person adjusts to a different way of seeing the world and prioritises different values.

65. Palliative Care endeavours to create a space where healing can occur. This healing clearly is not the same as cure. To create that space requires empathy, trust and building a relationship. Providing euthanasia as an option diverts the patient's attention, that of their family, diverts the attention of the doctor and the multidisciplinary team away from the inner work required for healing to occur. Over and again what we see is that when the problems are addressed, the idea of an early death is left behind.

66. Legalising euthanasia and assisted suicide would harm the very people that the palliative care/hospice services exist to help. It would undermine the relationship of trust between patient, family and health care provider that is essential to good palliative care. How can a patient trust the assurance that

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they will be cared for, that each problem they encounter will be addressed, that there is hope left in living, if at the same time they are being given the message that their life is hopeless and that it may be a good option to kill themselves instead.

67. Every day I spend hours with people who are facing death, who suffer, whom we help. The greatest need in my experience is to be truly heard, truly listened to, not abandoned emotionally or physically. People yearn so much to receive care unconditionally. They are acutely sensitive so to any signs that others feel they are a burden. If they sense in the slightest way that we do not care, they close down, retreat, their pain increases.

68. Euthanasia and assisted suicide are the complete opposite of palliative care. Someone who is suffering or in pain needs and deserves to have that addressed, to feel cared for and to hear the clear message that they are valued, that they will not be abandoned and that there is hope that their days will still have good in them. Offering death as a response negates that entirely.

69. Introducing physician assisted suicide and euthanasia would deeply compromise our ability to deliver high quality palliative care. I could not work effectively in that environment and I am aware that a high number of my colleagues, both physicians and nurses, have the same view (as expressed in the clear position statements of our professional bodies).

Legalising euthanasia and assisted suicide would undermine New Zealand's objectives for palliative care

70. Introducing physician assisted suicide and euthanasia would threaten the development of New Zealand's palliative care services to meet the needs of all New Zealanders.

71. The specialty practice of palliative medicine in New Zealand is recognised as a vulnerable area of practice by Health Workforce New Zealand due to lack of trained specialist medical staff in this country. New Zealand does not yet fund cohesive specialty training in this area, and not enough young doctors are being trained into palliative care to ensure sufficient staff are available in the future to meet even the present level of services, let alone to meet the expectation of all New Zealanders having full access to quality palliative care.

72. New Zealand is very dependent on recruiting and retaining experienced qualified palliative care specialists from overseas.

73. If New Zealand legalises physician assisted suicide and euthanasia, it is unlikely to be able to continue to attract the number and calibre of specialist practitioners that it has to date. I would not have come to practice here, and again I am aware that a high number of my colleagues overseas would not come here to practice in such an environment.

74. It also seems inevitable that with a reducing specialist work force and the budget pressures faced by the health system in New Zealand, the introduction of the fast and cheap solution of legalised euthanasia and assisted suicide would have a distorting effect on policy and funding decisions in health spending. Quality palliative care is challenging, and can be expensive especially when compared to euthanasia or assisted suicide.

Legalising euthanasia and assisted suicide would harm people with life limiting illnesses

75. Introducing physician assisted suicide and euthanasia would directly harm people with life limiting illnesses. I have outlined above how the delivery of palliative care would be compromised, which of course directly impacts on our patients. In this section I address the other direct harms that in my view would flow from legalising physician assisted suicide and euthanasia.

76. The most obvious harm is that people would die earlier than they would if allowed a natural death, because society fails to protect their right to live. While I understand that Ms Seales considers that she is in a position where she is able to choose with absolute freedom, my experience leads me to the firm view that most people with life limiting illnesses are not in that position. Their 'freedom' to opt for or against euthanasia or assisted suicide is likely to be compromised by a number of factors.

Pressure and coercion

77. All people with a life limiting illness are vulnerable, even those who are well educated and well supported by their families. Anyone who is ill is vulnerable to some extent, simply because they are less resilient and less physically robust. But those with cancer, for example, or other advanced illness are much more so: they are naturally anxious and frightened, and have a high level of

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dependency on family and friends for emotional, and sometimes physical, help and support. Being dependent like this can be the antithesis of how they lived their lives when they were well, and that can be difficult for some people to adjust to. People with illnesses such as this face higher risk of isolation, they tend to depend on others to come towards them with support and don't feel that they can ask or demand help or support.

78. People in this position are highly sensitive to any suggestion that they might be a burden.

79. Malpas et al's study[1] on the reasons older New Zealanders gave for supporting medical practices that hasten death entitled "I wouldn't want to become a nuisance under any circumstances" is attached as exhibit **"SMD-5"**. This study states its results as:

> An important finding of this study indicates that healthy, older individuals who support medical practices that hasten death have serious concerns about their (perceived) future incapacities and dependency on others, as well as their fears around becoming a burden. The study also found that fear of future pain was not a dominant reason to support medical assistance to die.

80. Agreeing to assist people to kill themselves is not a compassionate response to those who fear being a burden, who fear getting old or ill and losing their physical independence. Instead it sends the clearest message that they are correct to fear that society does not want them anymore and that their lives have no value and no meaning once they become frail. It sends the message that they are not worth our care and love. It sends the message that society agrees that it would be better for everyone if they were dead.

81. There is a real risk in my view that some people who would have lived longer if they had felt supported and cared for, would instead opt for assisted suicide or euthanasia. Others would feel pressure from family or society's expectations to take this option. There is also a real risk that others would be coerced, directly or indirectly, by those around them. Instead of protecting these people to ensure that their right to live out the full length of their lives and die a natural death was respected, we would be complicit in their early deaths.

82. Even with working with people and their families very closely through the palliative care process, there is no possible basis upon which I could assess

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[1] New Zealand Medical Journal 27 July 2013, Volume 125 Number 1358.

SD

whether a person who said that they wanted to die was completely free of any of these pressures, or was not subject to any coercion. I cannot see how a doctor with less contact, such as a GP, could safety make such an assessment: this is simply not a medical question.

Undiagnosed or untreated depression

83. This a problem because the features of depression are similar to symptoms and signs present in a patient with advanced progressive illnesses such as advanced cancer. The diagnosis of depression in an otherwise well patient depends on certain symptoms and signs eg fatigue, lack of appetite or poor sleep. Such symptoms and signs are frequently present in patients under palliative care. We frequently struggle to determine whether depression is present or not in patients receiving palliative care. Antidepressant medication can take some time to work (2-3 weeks), time which is often very limited for a patient with advanced cancer.

84. Even if depression were diagnosed, I am not sure how those supporting them could coherently persuade them that suicide is simply not an option and to hold to the hope that things will get better, when at the same time we are telling them that as soon as they are better from their depression, suicide is a good option.

Fear and ignorance of options

85. If euthanasia and assisted suicide were available and accepted as an appropriate response to a terminal diagnosis, there is a real risk that people will simply not engage with palliative care. People who would otherwise move through the early stages of grief at their diagnosis and come to find hope and meaning in their lives again would instead opt for an early death. For some people this loss would be of months or even years of their lives.

Other burdens and risks

86. Even if patients do engage in palliative care, the mind-set will have changed. Instead of working through the journey to a natural death, people would always have in front of them the prospect that it might be a better option for them to commit suicide or be euthanised. Engagement would be conditional. It is possible that it would not be supported by their families, or that families would divide on the issue, or that the decision would be argued and revisited

over and over again. All of this would be very damaging, and place enormous burdens and stresses on the person who is dying, and their family.

87. I also worry about the burden that this places on people who are already going through one of the most challenging stages of their life. Every day, to have the prospect of suicide before them, to have to decide anew whether their life is worth living, or whether this should be the day that they opt out. Contemplating suicide is a very bleak and hopeless place.

88. There is a real risk also that this would become a default position: people would shift to the mind-set that they have to justify to themselves (and possibly others) why they should stay alive. This is not a compassionate response to someone with a life limiting illness.

SWORN
at Wellington this 12th day of)
May 2015)
before me:)

Sinéad Maire Donnelly

Sinéad Maire Donnelly

Joyce Velasco

A ~~Solicitor of the~~ High Court of New Zealand

Deputy Registrar
of the High Court
of Wellington

"SMD-1"

Curriculum Vitae

Dr Sinéad Donnelly MD, FRCPI, FAChPM

April 2015

This is the exhibit marked "**SMD-1**" referred to in the affidavit of **Sinéad Marie Donnelly** affirmed at Wellington this 12th day of May 2015 before me:

Joyce Velasco
~~A Solicitor~~ of the High Court of New Zealand

Deputy Registrar
of the High Court
of Wellington

Personal Details

Name	Sinéad Máire Donnelly
Address	47 Chelmsford st, Ngaio, Wellington 6035 Aotearoa New Zealand

Medical Council Reg: 41835
(New Zealand)

CCST Accreditation date: January 31st 1999.

MB B.Ch. BAO	July '87, NUI, Galway.
ECFMG	1985/87.
MRCPI	November 1989.
MD	July 1996, NUI, Galway.
FRCPI	October 2001.
FAChPM	2010

Chair Irish Association Consultants Palliative Medicine 2007-2008

Executive Member Australia New Zealand Society Palliative Medicine(ANZSPM) Aotearoa 2009-2014. Deputy Chair 2010-2012, Chair 2012-2014, ANZSPM Council member 2010-2014

ANZSPM Aotearoa representative on Palliative Care Council, New Zealand 2014 ongoing

Examinations:

1980	1st place National University Ireland, Galway Entrance Scholarship awarded.
1981	Diplome de Langue superieure - mention tres honorable
University	MB, B.Ch, BAO - June 1987, NUI, Galway. ECFMG Part 1 - 1985 Part 2 - 1987
Post Graduate	MRCP Ireland - Nov 1989 MD - Quality of Life and Symptom Assessment in Patients with Advanced Cancer June 1996. FRCPI – October 2001. June 2006 – 1st Class Honours Higher Diploma Integrative & Humanistic Psychotherapy, University College, Cork, Ireland.

Undergraduate Experience

1981-2	1st Class Honours Pre-Med.
1982-3	1st class honours Anatomy Anatomy Class Demonstrator
1983-4	1st class honours Pharmacology
1984-5	1st class honours Kennedy Gold Medal Pathology/Microbiology 1st place - Experimental Medicine
1985-6	1st class honours - Gold Medal - Ophthalmology
1986-7	1st place Gold Medal - Obstetrics 1st place Gold Medal - Surgery 2nd class honours – Medicine.

POST GRADUATE EXPERIENCE:

CONSULTANT INTERNAL MEDICINE
Palliative Medicine Physician,
Clinical Senior Lecturer and Module Convenor Palliative Medicine,
Otago School of Medicine, Wellington
From July 2013 ongoing
Wellington Regional Hospital, Wellington, Aotearoa New Zealand

CONSULTANT PALLIATIVE MEDICINE

October 2008 to June 2013	Wellington Regional Hospital, New Zealand Advisor to PhD Candidate Committee University Otago, Wellington 2008-2012. Supervisor for successful MD candidate UCD, Ireland awarded Dec 2010. Adjunct Professor Biological Sciences, Victoria University, Wellington, 2010 ongoing Reviewer for Quarterly Journal of Medicine and New Zealand Medical Journal 2012 ongoing Awarded Special Purpose Grant of NZ$19,900 from Genesis Oncology Trust fund for 2010. Awarded New Zealand Cancer Society grant 2010 for Qualitative Research project in Wellington Regional Hospital Diploma Clinical research, Victoria University, wellington – Module Coordinator and Lecturer - Qualitative research 2012 ongoing
January 2000 – 2008	Consultant in Palliative Medicine Mid Western Health Board, Ireland. Led development of Palliative Medicine for the region. 20 bedded inpatient unit. Team of 4 non consultant hospital doctors including one Specialist registrar, 15 home care nurses covering 350,000 population Consultations to tertiary referral hospital plus 3 general hospitals

January 2006 - September 2008	Joined by second consultant with increase in specialist palliative care beds to 30, increase in team to 6 doctors training with 2 SpR, addition of outpatient service in the acute hospital.
June 2006 to Jan 2007	6 months – Te Omanga Hospice, locum Consultant in Palliative Medicine, Lower Hutt, New Zealand, and one week at Wellington Public Hospital, Wellington, New Zealand.
June 1999	Locum Consultant St Margaret's Hospice with sole medical responsibility for 25 bed palliative care unit, home care service provided by 2 McMillan nurses and day unit. Weekly teaching commitment to visiting final year medical students and postgraduate nurses. Since commencement on 1st June 1999, I have instituted combined ward rounds, weekly multidisciplinary meetings, staff teaching, an outpatient service, monthly research presentations, clinical collaboration with Beatson Oncology palliative medicine team. I am a member of a working party to design a 5 year palliative medicine curriculum for medical students at Glasgow University.
February 1999	Specialist Registrar Year 4 – St Margaret's Hospice, Clydebank has a 25 bedded palliative care unit, home care service and day care service. On a 1 in 5 rota. Affiliation with cardiology service of the Western Infirmary, attending weekly NYHA IV cardiac failure clinic. Weekly commitment to first and final year medical students as well as post graduate nurses. Fortnightly Specialist Registrar tutorials at the Beastson Oncology Centre.
August 1998	Specialist Registrar Year 4 at Beatson Oncology Centre, Western Infirmary, Glasgow. Rapidly developing palliative care consultative service. The trust includes a 135 bed oncology centre and 1,206 acute hospital beds serving approximately 2.5 million in the west of Scotland. The palliative care team of two physicians (consultant and specialist registrar - year 4) provides

24 hour 7 day care for inpatients and outpatients within this hospital complex as well as home care patients. Teaching commitment has involved postgraduate nursing and medical personnel. I am responsible for the palliative care service in the absence of the consultant.

August 1997

Specialist Registrar Year 3 West of Scotland Palliative Medicine. Experience gained in 40-bedded inpatient unit, day unit, outpatient, general hospital consultation, home care, 1 in 5 rota, under and post graduate teaching, supervision of junior medical staff, clinical research. Consultant level responsibility when Prof. Welsh absent. Experience gained at Yorkhill Paediatric Oncology Unit in paediatric palliative care. Practical training in management issues supplemented by day release formal teaching organised by the West of Scotland Postgraduate Medical board.

Jan 1995- June 1995
And
July 1996-June 1997

Registrar Palliative Medicine
Our Lady's Hospice
Harold's Cross
Dublin, Ireland

A post approved by the British Palliative Medicine Specialist Advisory Committee.
Responsible for 18 bed ward, part of 36-bedded unit including 4 beds dedicated to patients with AIDS. On call 1 in 4 rota to 36 bed unit. Six months experience gained in a busy home care service. Undergraduate and postgraduate teaching. Consultation to a major tertiary referral city hospital.

July 1995-June 1996

Completion of MD under the supervision of Prof. McCarthy UCG and Dr Declan Walsh Cleveland Clinic Foundation.

Oct 1992 - Dec 1994

Palliative Care Service M-76
Haematology/Oncology Dept
Cleveland Clinic Foundation

Cleveland, Ohio 44195, U.S.A.

Clinical Research Fellow.
During my fellowship the Palliative Care Service, established in 1987, treated over 500 new patients each year, referred as inpatients and outpatients. Most patients had advanced cancer; a small number having AIDS, progressive neurological disorders, end stage lung and cardiac disease. The service is structured as follows;
Inpatient consultation serving 1,000 bed tertiary referral centre. Inpatient care in 20 bedded unit.

Outpatient consultation.
Hospice home care with 24-hour cover
There is a strong research commitment with 2 research fellows, weekly research meeting, encouragement of all staff members to undertake research projects.

In addition to my research role I gained clinical experience with 20-hour weekly commitment to inpatient and outpatient services.

Published Work relevant to Palliative Medicine

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2. I cannot tell the truth, I can only tell what I know.
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   Seminars in Oncology 1995; 22:67-72

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   J Pall Care 1995; 11:27-32

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   Abstracts from Palliative Medicine Research forum
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   Donnelly SM, Walsh TD, Rybicki L
   Les Annales de Soins Palliatifs 1995; 3:4-17

10. The impact of cigarette smoking on long term survival and morbidity following bypass surgery for isolated stenosis of the left anterior descending coronary artery.
    Hennessy T, Codd M, Donnelly SM, Hartigan C, McCann H, Sugrue D
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18. Common Symptoms in Advanced Cancer,
Komurcu S, Nelson K, Walsh D, Donnelly S, Abdullah S, Homsi J.
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POSTER PRESENTATIONS

Symptoms in advanced cancer; effect of age and gender on symptoms and survival.

A. American Society of Clinical Oncology Texas 1994**
B. European Association of Palliative Care, Norway 1994
C. American Academy of Hospice Physicians Tennessee 1994
D. Palliative Care Research Forum Ireland 1994
E. National Scientific Meeting Royal College of Physicians Ireland 1996

**Merit Award Recipient 1994 ASCO
**American Cancer Society; speakers grant award 1994

Study of Quality of Life in Advanced Cancer
National Scientific Meeting, Royal College of Physicians, Ireland 1996

European Association of Palliative Care – Palermo 31st March 2001.
Folklore associated with Dying in the west of Scotland.
Folklore associated with Dying in the West of Ireland.

Moment of Death – a Qualitative Enquiry – 14th International Congress on Care of the Terminally Ill, Montreal, Canada – October 2002.

Moment of Death – a Qualitative Enquiry – Health Promoting Hospitals: Public Perspective & Participation – October 2002 – Donegal, Ireland.

Moment of Death - presented at International Conference - Health Promoting Hospitals - Florence, May 2003.

Aachen EAPC – Moment of Death: Carer's experience of death at home April 2005.

May 2006 – EAPC – Venice - Moment of Death: Carer's experience of death at home, Dr. S. Donnelly and Dr. N. Michael, Dr. C. Donnelly.

May 2010 – EAPC – Glasgow – Dying in hospital – It's never easy to have the conversation. MacLennan A, Levack W, Hudson S, Dean S, dew K, Donnelly S.

February 2011 – International Cancer Conference in conjunction with Mayo Clinic – Wellington
Relatives matched with staff's experience of the moment of death in a tertiary referral hospital - M Dickson, S Donnelly

May 2015 European Association Palliative Care, Copenhagen. Relatives' and staff's experience of dying in ICU. S Donnelly, A Psirides

Seven Documentaries

Produced by Sinead Donnelly:

1st documentary ANAM; story of a cultural soul– Documentary on Irish Philosophy of suffering and dying. Executive Producer/Director S. Donnelly– 2002. Broadcast on TG4 on 31st October 2002.
Anam also presented at Health Promoting Hospitals International Conference Florence, May 2003. Broadcast Irish language television station 2002.

2nd documentary **Give me Your Hands** – Broadcast RTE June 2004 (145,000 viewers).

3rd Documentary A Child's Grief. accepted for the Galway Film Festival/Fleadh 2006. Broadcast RTE National television June 2006

4th Documentary **"Going Home"** exploring the experience of caring for relative dying at home, RTE 1 broadcast November 23rd 2008

5th Documentary completed 2009 describing the experience of relatives caring for someone dying at home in New Zealand. Broadcast Maori Television June 20th, 2010

2010 New Zealand Cancer Society: $ 2,000 grant received to fund 6th short documentary on 4th year medical students' visits to patients in a hospice. **"I feel light as I close the hospice door…"**
This documentary shown at:
February 2011 Cancer Conference in Wellington,
May 2011 New Zealand Hospital Palliative Care Annual Meeting, Wellington.

7th documentary **"The Last Mile Home"** exploring patient and family opposition to legalisation of euthanasia. Presented at Victoria University Law School seminar Feb 7th, 2013. Distributed for teaching purposes.

Grants Awarded

2009 Genesis Oncology $19,900

2010 New Zealand Cancer Society: $ 2,000 grant received to fund 6th short documentary on 4th year medical students' visits to patients in a hospice. "I feel light as I close the hospice door…"

2011 Genesis Oncology $4,500 to enable Dr M Dickson co present with Dr S Donnelly at Montreal conference Oct 2012

2012 Wellington Hospital Foundation Research Grant $1,000 to provide administrative support for research in progress: Relatives matched with staff's experience of the moment of death in the ICU of a tertiary referral hospital

REFERREES

Dr Anne O'Donnell MD, FRACP
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Clinical Leader Oncology Department
Wellington Regional Hospital
Wellington 6242, Aotearoa New Zealand
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Western General Hospital
Crewe Rd
Edinburgh EH4
Scotland

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E-mail marie.fallon@ed.ac.uk

"SMD-2"

The New Zealand Palliative Care Strategy

This is the exhibit marked "**SMD-2**" referred to in the affidavit of **Sinéad Marie Donnelly** affirmed at Wellington this 12 day of May 2015 before me:

Joyce Velasco

A ~~Solicitor~~ of the High Court of New Zealand

Deputy Registrar
of the High Court
of Wellington

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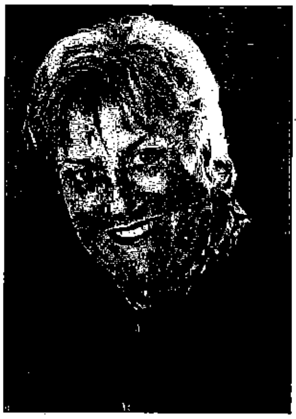
Front Cover Sketch:
Tinakori St Sketch by Ian Donovan, patient of Te Omanga Hospice

Foreword



The New Zealand Palliative Care Strategy sets in place a systematic and informed approach to the future provision and funding of palliative care services. This Government is concerned to ensure that all people who are dying and their family/whānau have access to palliative care services, provided in a co-ordinated and culturally appropriate way. That is why this Government has committed additional funding to ensure that the strategy can begin to be implemented immediately.

The health and disability sector is currently being reconfigured to increase local decision-making and improve the responsiveness of health funders and providers to their communities. These changes also signal a need for communities, providers and funders to work together at a local level to ensure that services in their area make sense and are focused on the needs of the population. I would therefore like to encourage communities and all providers of palliative care to start working together to ensure the Palliative Care Strategy is implemented in the most optimal way, both in your local area and across the country.

Many people have assisted in the development of the strategy by providing feedback on the discussion document and, in particular, by serving on the sector advisory group. I would like to take the opportunity to thank all these people. I would also like to thank all those involved with the delivery of palliative care services, especially the many volunteers who give of their time to assist and be with people who are dying.

A significant amount of work needs to be undertaken in order to implement the New Zealand Palliative Care Strategy. I look forward to your continued involvement and enthusiasm in carrying forward the vision and strategies outlined in this document.

Annette King

Hon Annette King
Minister of Health

Contents

Appendices

Executive Summary

Palliative care is the care of people who are dying from active, progressive diseases or other conditions that are not responsive to curative treatment. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing – tinana, whānau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care also supports the bereaved family/whānau.

This palliative care strategy has been developed because:

- evidence shows that palliative care is effective in improving the quality of life for people who are dying
- palliative care needs to be better understood and accepted by health professionals so that dying people have timely access to palliative care
- there is a demonstrable need for palliative care now and increasingly into the future
- palliative care provision is complex, and a range of issues need to be addressed.

The aim of the strategy is to set in place a systematic and informed approach to the provision and funding of palliative care services through the implementation of the following vision:

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

In order to implement this vision there is a fundamental need to raise the profile of palliative care among communities and health and disability providers, to increase the awareness of palliative care services among communities, and to develop a 'palliative care culture'. Underpinning this is the development of:

- *a set of essential services for dying people who could benefit from palliative care.* These services would include assessment (initial and ongoing), care co-ordination, clinical care and support care
- *a flexible service configuration* that builds on existing services, takes account of the future direction for primary care, and is co-ordinated to ensure that dying people have access to all essential services via two inter-linked levels of palliative care services that include:
  - local palliative care services provided from each District Health Board area, which provide access to the essential services for people who are dying
  - specialist palliative care services in each region, particularly in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin. These providers would have particular responsibility for providing the specialist palliative care advice for the region, maintaining linkages with the tertiary hospitals and undertaking regional and national quality improvement and educational activities.

Nine strategies have been developed which will be implemented over a 5–10-year period in order of priority. The first priorities will be to ensure that essential services are available for all dying people and that at least one local palliative care service is available in each District Health Board. Additional funding has enabled the implementation of these strategies to be started.

The other strategies will be implemented in line with other government priorities outlined in the New Zealand Health Strategy.

1 Introduction

Background

In September 1999 the Ministry of Health and Health Funding Authority (HFA) commenced work on a 5–10-year strategy for palliative care services. The need for a strategy was identified in response to an increasing number of problems and issues identified by providers (particularly hospices), Hospice New Zealand, previous reports and working parties. The strategy development was also an opportunity to conclude aspects of the Care of the Dying project that was undertaken by the National Health Committee from 1997 (see Appendix 1).

In developing the strategy document the project team undertook extensive consultation and analysis, which included literature searches, analysis of previous reports, needs analysis, the use of contract and questionnaire information on palliative care service provision (hospice and hospital), an informal telephone survey of Independent Practitioner Associations (IPAs), informal discussions with stakeholders (providers and interest groups), a Māori working party, and informal discussions with a range of providers and interest groups.

An eight-person expert advisory group was appointed to assist the project team (see Appendix 2). In addition, a reference group was established to complement the expertise of the advisory group, to ensure representative advice from all involved with palliative care.

In mid-July 2000 over 1900 Palliative Care Strategy discussion documents were mailed out to stakeholders and sector interest groups. In response 116 groups and individuals provided a written submission on the discussion document. There were also 12 public meetings and focus group meetings around New Zealand to gain direct feedback from the public, providers, carers and people receiving palliative care. An analysis of the submissions has been distributed to those who made written submissions.[1]

This strategy has been developed with the assistance of the expert advisory group and using feedback from the written submissions and the meetings (see Appendix 3).

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[1] Copies are available from the Ministry of Health, or can be found on the Ministry Web site: www.moh.govt.nz.

What is palliative care?

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

- affirms life and regards dying as a normal process
- aims neither to hasten nor to postpone death
- aims to provide relief from distressing symptoms
- integrates physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life
- offers help to the family/whānau/carers during the person's illness and their bereavement.

Principles of palliative care

There are five guiding principles that underpin the above definition.

- The focus of palliative care is the person who is dying as well as their family/ whānau.
- All dying people should be informed of their entitlement to palliative care and have access to quality health and support services appropriate to, and consistent with, their needs.
- Each person's uniqueness, culture and autonomy should be respected, with all care based on their expressed needs and wishes.
- Palliative care affirms and encourages the quality of life for each individual. While interventions (such as radiotherapy, chemotherapy and surgery) have a place in palliative care, the symptomatic benefit should outweigh any disadvantages of the procedure.
- The achievement of total care for the person requires both a multidisciplinary approach and continuity of care (before, during and after diagnosis of the terminal illness).

When should palliative care services commence?

It is not always easy to know when the provision of palliative care services should commence. Some people may live for many years with an illness or condition that is not curable and yet they may not be in the terminal phase of their illness.

The palliative approach assists health professionals to determine the stage in a person's illness or condition when palliative care services are needed. This is a holistic approach to care, informed by the knowledge and practice of palliative care principles, and which promotes a person's physical, psychological and social wellbeing (Doyle 1990; Llewellyn et al 1999). The palliative approach assists a health professional recognise all the care needs of a person from the time of diagnosis, as well as informing the decision on when to commence discussing referral to palliative care services with a dying person and their family/whānau.

This strategy recommends that palliative care should generally be available to people whose death from progressive disease is likely within 12 months. The introduction of palliative care or referral of a person to palliative care services should be:

- guided by referral protocols
- supported by the advice of a health professional, and, most importantly
- based on the person's needs and choices.

Until people require palliative care it is important that they receive appropriate support care and clinical care to enable them to maintain their independence for as long as possible or desired. This strategy recognises that further work needs to be undertaken to address the needs of those with chronic and disabling diseases/conditions, particularly in relation to the type of services needed for those who do not yet require palliative care.

Why a palliative care strategy?

A palliative care strategy is necessary because of the following factors.

Palliative care is effective

Palliative care is globally recognised as a legitimate component of health care. Evidence shows that palliative care is effective in improving the quality of life for people who are dying, and that it should be a central feature of all good clinical practice (WHO 1990; NCHSPCS 1994; Bruera et al 1999; Higginson et al 2000). In New Zealand, palliative care has not always been well understood or accepted by providers and incorporated into clinical practice. This is particularly so in some hospital services, primary care services, rest homes and private hospitals. Some dying people may therefore not be in a position to make an informed choice about their care (as required under the Code of Health and Disability Services Consumers' Rights). A strategy is therefore needed to raise awareness about the effectiveness of palliative care among health and disability professionals and providers and the general population.

Increasing need for palliative care services

At present approximately 90 percent of people known to be accessing hospice palliative care services have cancer, and the large majority of these people are aged 60 years and over (this age group accounts for 78.8 percent of cancer deaths). The proportion of the population aged 65 or over is projected to more than double (from 12 percent to 26 percent) over the next 50 years. It is also estimated that by 2011 the number of people with cancer will increase by 24 percent. There will thus need to be sufficient palliative care services to meet the needs of an increasing number of people with cancer.

In addition, there is an increasing awareness that people with non-malignant diseases can benefit from palliative care services. Currently only 10 percent of those people accessing hospice services have non-malignant diseases, but many more people with non-malignant diseases could benefit from them. It is estimated that if all the people with non-malignant diseases accessed hospice services, the numbers accessing the services would double. This could place a heavy burden on palliative care services if they are not resourced to manage this (see Appendix 4 for an overview of palliative care services).

Service issues need to be addressed

There are a number of factors preventing the delivery of good palliative care to people who are dying and their families/whānau, including:

- lack of a palliative care approach in some services
- variable access to palliative care services due to:
  - service gaps and national variation in different aspects of care
  - lack of recognition that people who are dying from conditions other than cancer can benefit from palliative care services
  - cultural barriers, in particular for Māori and Pacific peoples
  - lack of services in rural areas
  - lack of services designed for children and young people
  - interface, framework and funding boundaries between personal health and disability support services
- poor integration and lack of co-ordination of palliative care services, making for service variability
- lack of standard quality specifications or performance indicators/outcome measures, making benchmarking impossible
- lack of workforce planning for palliative care (there are not enough palliative care specialists in New Zealand and relatively few palliative care health professionals for Māori and Pacific peoples)
- variability in the funding of palliative care services, particularly for hospices that are not fully funded by government.

See Appendix 5 for more detail.

The Palliative Care Strategy in context

The health and disability sector has been reconfigured to increase local decision-making and improve the responsiveness of health funders and providers to their communities. The HFA and the Ministry of Health have been amalgamated, and funding is to be devolved to 21 District Health Boards (DHBs), which are currently being established. DHBs will be responsible for working within allocated resources to ensure that services reflect the needs of individuals and communities at a local level. Each DHB will enter a funding agreement with the Crown. This agreement will outline the Crown's expectations of each DHB in relation to the services that should be funded and provided. The new sector is designed to take a more integrated and co-operative approach to health care.

The changes are being guided by the New Zealand Health Strategy (Minister of Health 2000), which provides an overarching framework for the health sector. This strategy outlines seven fundamental principles for the health sector as well as key goals and objectives.

The Government has identified 62 objectives for the health sector. Of these, 13 population health objectives have been highlighted for the Ministry of Health and DHBs to focus on for action in the short to medium term.

The New Zealand Health Strategy's priority population health objectives:

- to reduce smoking
- to improve nutrition
- to reduce obesity
- to increase the level of physical activity
- to reduce the rate of suicides and suicide attempts
- to minimise harm caused by alcohol, illicit and other drug use to both individuals and the community
- to reduce the incidence and impact of cancer
- to reduce the incidence and impact of cardiovascular disease
- to reduce the incidence and impact of diabetes
- to improve oral health
- to reduce violence in interpersonal relationships, families, schools and communities
- to improve the health status of people with severe mental illness
- to ensure access to appropriate child health care services, including well child and family health care, and immunisation.

The strategy also highlights three priority objectives to reduce disparities in health status. These are:

- to ensure accessible and appropriate services for people from lower socioeconomic groups
- to ensure accessible and appropriate services for Māori
- to ensure accessible and appropriate services for Pacific peoples.

In addition to the above priority objectives the New Zealand Health Strategy highlights five service delivery areas the Government wishes the health sector to concentrate on in the short to medium term:

- public health
- primary health care
- reducing waiting times for public hospital elective services

- improving the responsiveness of mental health services
- accessible and appropriate services for people living in rural areas.

One of the 62 objectives that the Government has highlighted is to ensure access to appropriate palliative care services. As palliative care is not one of the priority service or population areas, full implementation of this strategy will occur in the medium term rather than the short term. Priority will, however, be given to the most urgent issues facing palliative care; that is, filling service gaps and integration of services (see Strategies to Implement the Vision). Additional funding of $7.5 million per annum has been provided for this purpose.

The New Zealand Disability Strategy will be implemented alongside the New Zealand Health Strategy once it has been developed. The Disability Strategy aims to help open the way into community life for people experiencing disability by removing the barriers to their participation.

Both the New Zealand Health Strategy and the New Zealand Disability Strategy acknowledge the special relationship between Māori and the Crown under the Treaty of Waitangi.

Central to the Treaty relationship and the implementation of Treaty principles is a common understanding that Māori and the Crown will have a shared role in implementing health strategies for Māori. The draft Māori Health Strategy outlines the three key principles for achieving Māori health gain: *partnership, participation* and *protection*.

The Government is also committed to developing a number of other strategies that will be implemented alongside the Palliative Care Strategy and under the umbrella of the New Zealand Health Strategy and the New Zealand Disability Strategy. These include the Pacific Health Strategy, the Primary Health Care Strategy and the Health of Older Person's Strategy.

Aim of the Palliative Care Strategy

The aim of the strategy is to set in place a systematic and informed approach to the provision and funding of palliative care services. In developing this strategy, key objectives are to:

- develop a practical strategy that builds on current service arrangements (including services provided by hospices, hospitals, GPs, district nurses, Māori health providers, home support, rest home, aged care hospital and charitable organisations such as the Cancer Society, Multiple Sclerosis Society and Motor-Neurone Disease Association)
- develop a more responsive system that can support a person's choice to die at home: research shows that 50 to 70 percent of people would prefer to have the choice of home care; at present, only 31 percent of people with cancer die at home (although for Māori and Pacific peoples the figure is 53 and 42 percent respectively)
- raise awareness of the importance of good palliative care
- incorporate work already done in relation to palliative care (Ministry of Health 1993, 1998; Robertshaw 1994; Penny 1997)
- learn from overseas directions in palliative care, which point to the need for more co-ordination and integration of services (NCHSPCS 1997; Palliative Care Australia 1998; Nichols 1998; Bruera 1999; Hospice NZ 1998) (see Appendix 6).

2 A Vision for Palliative Care Services in New Zealand

The vision for the provision of palliative care services in New Zealand is that:

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

Underpinning the vision is a community model of palliative care services. This means 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 order to implement the vision there is a fundamental need to develop an awareness and knowledge of palliative care among communities and providers of health and disability services. There is also a need to identify clearly:

- the essential and accessible palliative care services for people who are dying and their family/whānau
- the service configuration required to ensure access to co-ordinated quality palliative care services that are culturally appropriate.

Access to the essential palliative care services

A set of essential services that dying people and their families/whānau should have access to has been developed. This set of services is consistent with overseas practice and current thinking in New Zealand (NCHSPCS 1997; Palliative Care Australia 1998; Nichols 1998; Burera 1999; Hospice NZ 1998). It also recognises that for people to have the option of dying at home there must be access to a range of services provided in the community.

The Government is committed to funding essential palliative care services to ensure that services are available. It should be noted, however, that services provided to dying people by primary care providers who are not part of palliative care services will be addressed as part of the Primary Health Care Strategy, which will recommend that over time the Government will commit additional funding to primary care.

The essential palliative care services that dying people and their families/whānau should have access to are described below.

Assessment and care co-ordination

Assessment

Following confirmation that a person's illness or condition has reached its terminal stage, the dying person should have an initial multidisciplinary assessment to identify the person's and their family/whānau's physical, social, spiritual and emotional needs. Following this initial assessment, there should be ongoing assessment by team members directly involved in the person's care. A multidisciplinary assessment is important to ensure that all needs are identified early, and that an individualised care plan is established. It is important that the multidisciplinary team include the GP/practice nurse of the dying person to ensure continuity of care.

Care co-ordination

Each person who is dying should be allocated a care co-ordinator at, or following, the initial assessment. The care co-ordinator is responsible for ensuring that the dying person and their family/whānau are provided with information regarding palliative care options and services, and that the family/whānau are provided with the necessary information and skills to assist in caring for their dying family member.

The care co-ordinator also has responsibility for co-ordinating and ensuring access to the appropriate palliative care and other services, including:

- specialist palliative care
- primary care services
- hospital services
- Māori provider services
- residential care services
- home support
- services provided by social support agencies (for example, Work and Income New Zealand)
- voluntary services (for example, Cancer Society, MS Society and Motor-Neurone Society).

The care co-ordinator will ensure care is appropriate to the person's needs and culture. They will have responsibility for promulgating the palliative care approach and for liaising with and maintaining working relationships with all providers and volunteers.

Clinical care

Each person who is dying should have access to clinical care that includes:

- access to medical services (including primary care and specialist services), domiciliary nursing services, and equipment to provide symptom control, nursing and medical management 24 hours a day, seven days a week, in the community
- access to inpatient care for respite care and/or control of symptoms that cannot be adequately controlled in a community setting; inpatient care should also be provided if required or preferred
- bereavement counselling and spiritual care for the person, and for their family/whānau, before and after death to assist them to work through their bereavement.

Support care

People who are dying and their families/whānau should have access to support services based on need, including:

- support in the home (for example, picking children up from school, general household management)
- long-term residential care in an appropriate setting for people who are unable to be cared for in the home. Most older people accessing residential care with palliative care needs currently undergo income and asset testing, as do other older people accessing rest home care.

Service configuration for palliative care services

A service-based framework is required which ensures that dying people and their family/ whānau can access the essential palliative care services they require.

This framework needs to:

- build on the existing services and workforce
- integrate/co-ordinate services at a local, regional and national level to ensure continuity of care
- ensure that all palliative care services are culturally appropriate for all population groupings, including Māori and Pacific peoples
- ensure the quality of palliative care services
- provide the flexibility to meet people's needs, including for those who do not wish to die at home
- take account of the future direction for primary health care.

On this last point, the Primary Health Care Strategy outlines six key directions for the primary health sector. The local structures to achieve these directions will be Primary Health Organisations. People will be encouraged to join a Primary Health Organisation by enrolling with a provider of primary care services such as a general practice or local health clinic. The roles of Primary Health Organisations include improving and maintaining the health of their enrolled population, providing first-line services to people when they are unwell, providing continuity of care, working in a multidisciplinary team and responding to the needs to their populations.

Palliative care service networks

To ensure that dying people and their family/whānau have access to the essential palliative care services, a service framework with a network of two inter-linked levels of palliative care services is required:

- local palliative care services
- specialist palliative care services.

Local palliative care services

Each DHB area will be required to have at least one provider that provides palliative care services at a local level. These providers should be able to meet most of the palliative care needs of the community.

Providers of local palliative care services may be a hospice, a hospital community-based service and/or a primary health organisations. Each will be required to:

- provide access to the essential palliative care services in both community and institutional settings for their DHB area in line with the Funding Agreement between DHBs and the Minister of Health
- have a formal agreement with specialist palliative care services in line with specialised palliative care services outlined below
- have formal links with relevant service providers in the area, including hospital services, primary care services, Māori providers, Primary Health Organisations and disability support service providers
- develop a plan with local Māori to ensure there is appropriate access to the palliative care services that Māori need.

People requiring local palliative care services are likely to be either self referred or referred from a number of services, including primary care, Māori provider organisations, hospitals, rest homes, and community provider organisations. It is important that these providers understand and utilise the palliative care approach to ensure that a timely referral to palliative care services is made.

GPs and primary health care nurses are very important in providing continuity of care for the dying person and their family/whānau. Primary care providers should be part of the palliative care multidisciplinary team and local palliative care service. Community support providers should also be considered part of this team and service.

Providers who do not have respite or long-term care beds will need to have formal links with rest homes or private hospitals and should have the responsibility for ensuring the person receives quality palliative care services.

It is important that where there is more than one provider, services are well co-ordinated to ensure that the dying person and their family/whānau receive seamless care.

Specialist palliative care services

All DHBs should have access to specialist palliative care services, but it will not be possible for all DHBs to provide these services directly. To ensure an appropriate level of access there should be at least six specialist palliative care services based in Auckland, Hamilton, Palmerston North, Wellington, Christchurch and Dunedin, where:

- there can be close geographical proximity to tertiary hospital services
- there are existing hospices/hospital services in these regions that provide specialised palliative care.

Providers of specialist palliative care services are likely to be either a hospice, a hospital or both of these service providers working together. Specialist palliative care service providers will provide the essential services for their community and a full range of specialist palliative care services which include:

- providing evidenced-based specialist advice to local palliative care providers, on-site care and consultation where necessary
- establishing effective links with local palliative care providers in the region
- facilitating quality improvement in all local palliative care providers in the region
- ensuring that appropriate specialist education and training is available (this would include the provision of clinical placements for medical and nursing staff)
- establishing effective links with specialist palliative care services nationally and undertaking national work on quality improvement activities (for example, developing evidenced-based referral and best-practice guidelines, developing outcome/performance indicators and undertaking benchmarking activities)
- undertaking/participating in palliative care research activities.

Specialist palliative care services will employ health professionals with a broad range of palliative care competencies, including:

- two or more full-time equivalent doctors with a recognised palliative care specialist qualification
- a majority (over 60 percent) of their registered nursing staff with a recognised palliative care qualification and the rest working towards completed palliative care qualifications
- one or more trained bereavement counsellors with skills in palliative care
- access to trained occupational therapists, physiotherapists and pharmacists with palliative care expertise.

Specialist palliative care services will have to meet the Health and Disability Sector Standards before being eligible to be recognised as a specialist palliative care service. It is also likely that they would be either accredited or working towards accreditation using Quality Health's Palliative Care Standards.

Specialist palliative care services will also have formal links with hospital palliative care teams. These teams, while linked to specialist palliative care services, will work in the tertiary hospitals. Hospital palliative care teams are necessary to educate and advise all hospital services on the palliative care approach and the need to provide palliative care as an option for people who are dying. They will also assist hospital providers in ensuring that people access the appropriate palliative care service in their communities.

While hospital palliative care teams will initially operate in the tertiary hospitals, it is expected that over time all hospitals will have the presence of health professionals with palliative care training/ experience.

Role of the community

This strategy recognises that community organisations and volunteers play an important part in the delivery of palliative care services. It recognises the many hours that volunteers contribute in caring for those who are dying and strongly supports the continued role of volunteers. This strategy also recognises that volunteers play an important role in reflecting community values and ownership in health service provision. It is important, however, that where volunteers are assisting in palliative care services, appropriate induction and ongoing training is made available. Hospice New Zealand is currently undertaking national work on volunteer education.

Needs of specific population groups

While most of the people requiring palliative care are older and have varying needs, some other population groups have specific needs. The needs of Māori, Pacific peoples, people with disabilities and non-malignant disease, people under the age of 65, and children are outlined below. Other groups will also have specific needs, so it is important that palliative care services be flexible enough to ensure that all needs are met.

Māori

In order to address the needs of Māori, it is important that:

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

Pacific peoples

Palliative care services and other health services need to understand Pacific cultures in terms of care of the dying. It is also important that Pacific peoples have information about palliative care services. Where there is a high Pacific population it is important that palliative care services recruit Pacific health professionals and volunteers. It is recognised, however, that there are very few trained Pacific health professionals and there is a need for more to be trained.

People with disabilities and non-malignant disease

It is important that palliative care services recognise the palliative care needs of people with disabilities and those with non-malignant disease (for example, those with motor neurone disease, multiple sclerosis and chronic obstructive airways disease). These diseases are often longer in duration than diseases such as cancer and often require a higher level and complexity of support care. There is a need to consider the availability and suitability of support services and other services for these people following diagnosis of their condition and prior to their receiving palliative care services. There is also a need to ensure they have timely access to palliative care services when they require it.

People under the age of 65

Local palliative care services and community support services should generally be able to meet the palliative care needs for people under the age of 65.

A small proportion of these people cannot be cared for at home and require longer-term inpatient care. Residential care services, which mainly cater for older people, are not always suitable for this population group. When organising longer-term care for people under the age of 65 it is important that palliative care services consider the suitability of the available services.

Children

Children require different palliative care services. Children who are dying need the expertise of a paediatrician and paediatric nurse with palliative care experience.

The *Paediatric Review* identified a need for a children's care co-ordinator at the local level. The care co-ordinator needs to have experience in paediatrics and palliative care and to be part of a multidisciplinary team, which includes a paediatrician and paediatric nurses.

Given that only a very small number of children need to access palliative care compared to adults, and that their needs often require highly specialised services, this strategy supports the implementation of the recommendations from the *Paediatric Review*. These include:

- the development of a national network for those involved in paediatric palliative care and a working group of representatives, both to advise on the national standards of care required and to monitor these standards
- the development of a national palliative care team to provide expert advice to local teams (this has been in part implemented with the appointment of the child palliative care team at Starship Hospital, which has both a regional and national role)
- the employment of a co-ordinator of paediatric palliative care for each local specialist child health team and each paediatric oncology unit
- recognition that much of the care will be delivered by local specialist child primary health teams.

While this strategy is supportive of the national palliative care team and local teams (including co-ordinators) for children, it is important they have formal links with local and specialist providers of palliative care services for adults. This linkage should assist with sharing expertise and ensuring that children receive appropriate bereavement counselling if a parent dies.

Summary

The vision for palliative care is: '*all* people who are dying who could benefit from palliative care and their family/whānau should have timely access to quality palliative care services that are culturally appropriate and provided in a co-ordinated way'. This vision is underpinned by four key features:

- an awareness and knowledge of palliative care among communities and providers of health and disability services
- the provision of essential palliative care services for people who are dying and their family/whānau (these include care co-ordination to ensure that services are co-ordinated and appropriate for each individual)
- a framework that is based around a palliative care network comprising two inter-linked levels of care
- well co-ordinated and flexible service arrangements to ensure that the needs of all different population groupings can be met.

3 Strategies to Implement the Vision

The strategies below have been developed to ensure that quality palliative care services based on need are available for all New Zealanders. While additional funding for palliative care services may eventually come from savings made through fewer expensive interventions and fewer inappropriate acute admissions for people who are dying, in the shorter term it is recognised that additional funding is required to implement these strategies.

However, this is a 5–10-year vision, and most of the strategies outlined will require a significant amount of lead-time for implementation. As the Government has identified that the 13 priorities within the New Zealand Health Strategy will take priority in the short to medium term, it is important that the implementation of the New Zealand Palliative Care Strategy focuses first on the most urgent strategies.

In implementing the strategies an important aim is to build a 'palliative care culture' in which:

- all providers, where necessary, adopt a palliative care approach
- there are good linkages with and between palliative care service providers
- people are aware of the palliative care services that are available in their communities.

Strategy 1:
Ensure access to essential palliative care services

This is the first priority for the implementation of the palliative care strategy. Essential services include assessment and care co-ordination, clinical care and support care.

Additional funding for palliative care services has enabled this strategy to be partly achieved already. Purchase units, a service specification and a pricing model for hospice palliative care services have been developed by the HFA and are currently being implemented in line with the New Zealand Palliative Care Strategy. As palliative care services vary in their provision of services, ongoing work on the pricing model will be undertaken by the Ministry of Health. Palliative care providers will be required to provide ongoing information for this purpose.

Additional work being undertaken by the Ministry of Health includes the identification of gaps in essential services (including rural areas) and the capacity in each area for providing essential services. Using the extra funding for palliative care services ($7.5 million per annum), the extent to which service gaps can be filled in each DHB area is currently being determined. DHBs continue this work as a requirement of the Funding Agreement between the Minister of Health and each DHB.

Additional work needs to be done to ensure that dying people have access to the support services they need. This work includes a review of disability support services which analyses:

- the extent to which interface and boundary issues between personal health and disability support services influence access to support services
- how many people are currently accessing personal health and disability support services, and what gaps there are in community support services that will require additional funding
- the extent to which existing community support services are robust enough to provide ongoing support for people with a palliative care need
- the extent to which existing residential care services can be utilised to provide both short-term and long-term residential support for dying people; this needs to be done in relation to those people under and over 65
- the costs of providing support services.

This work needs to wait until high-level policy decisions have been made on whether funding for services for older people will move to Personal and Family Health, as this would change the funding boundaries and have an impact on the nature of the work to be undertaken.

Strategy 2:
Each DHB to have at least one local palliative care service

This strategy needs to be implemented alongside Strategy 1.

In a number of places, providers – particularly hospices – already fulfil most of the requirements necessary to be a local palliative care service. In other places, particularly rural areas, providers may need to work together or co-ordinate with each other to provide the essential services. For example, primary care providers could link up with district nursing services.

Each DHB will need to develop a plan that identifies:

- local needs for palliative care
- local service providers (including Māori providers), service provision and capacity to provide all the essential services, including support services
- justification of the choice of providers for delivering local palliative care services.

DHBs will be able to build on the work already started by the HFA. In particular they will need to utilise the information on needs analysis and service provision collected by the Ministry of Health.

Strategy 3:
Develop specialist palliative care services

This strategy is a medium-term priority in line with the New Zealand Health Strategy, and will be implemented after Strategies 1 and 2.

Each DHB should have access to a specialist palliative care service. It is recommended that there be at least one specialist palliative care service in Auckland, Waikato, Palmerston North, Wellington, Christchurch and Dunedin to ensure appropriate geographical access for communities.

Specialist palliative care services will provide local services for their community, but will also have additional responsibilities for providing evidenced-based specialist advice, facilitating quality improvement among local palliative care providers, and providing specialist education and training for medical and nursing staff. They also have responsibility for working with specialist palliative care services nationally on quality improvement activities.

Specialist palliative care services can be provided by a hospice or hospital, or a joint-arrangement between these organisations. The development of these services can be achieved through:

- the development of purchase units and service specifications for additional services offered by providers of specialist palliative care services. (The price and cost of services will need to be determined. This work will be done by the Ministry of Health in conjunction with DHBs and palliative care providers)
- DHBs working together to identify likely providers for the specialist palliative care service in the region in conjunction with palliative care providers
- the establishment of a timeframe and plan by DHBs for implementing the specialist palliative care service
- DHBs working with providers in the region to establish the specialist palliative care service and network.

Strategy 4:
Implement hospital palliative care teams

This strategy should be developed alongside Strategy 3.

Hospital palliative care teams have a particularly important role in ensuring that the palliative care option is available for dying people, as well as in providing advice and assistance to staff in hospitals on the care of dying people. They also have an important role in co-ordinating services for the dying person and their family/whānau to ensure they receive services when they are discharged from hospital.

Hospital palliative care teams will have formal links with the specialist and local palliative care services but are likely to be employed by the hospital.

Currently there are four existing hospital palliative care teams based in Auckland, Waikato, Christchurch and Wellington. The implementation of hospital palliative care teams across the country can be achieved through the development of purchase units and service specifications for hospital palliative care teams, and calculation of the price and cost of the service. This work will be done by the Ministry of Health in conjunction with DHBs and will include:

- the identification of hospital services that currently utilise or will utilise hospital palliative care teams
- the identification of existing sources of hospital funding for hospital palliative care teams based on current contract lines and the calculation of any additional funding that may be necessary
- the implementation of hospital palliative care teams in those tertiary hospitals that do not currently have hospital palliative care teams.

Strategy 5:
Develop quality requirements for palliative care services

This strategy will be implemented alongside Strategies 1 to 4.

In order to assure the quality of palliative care services, the following need to occur.

- DHBs will have to monitor palliative care providers to ensure that they meet the quality requirements as detailed in contracts.
- DHBs will have to ensure that palliative care providers are working towards meeting the Health and Disability Sector Standards. Once the legislation is in place, palliative care providers will be audited (by the appropriate service) to ensure that they meet the standards and legislative requirements.
- Specialist palliative care services (once fully implemented) will take responsibility for:
  - promoting an evidence-based approach to the provision of palliative care across all palliative care services in the region
  - developing referral and best-practice guidelines
  - developing outcome measures/performance indicators for palliative care services
  - undertaking national benchmarking activities across palliative care services, including audit.

The above activities will occur in conjunction with the professional colleges and national organisations, particularly Hospice New Zealand.

Strategy 6:
Inform the public about palliative care services

This strategy will be implemented following Strategies 1 to 4 in consultation with relevant national organisations, including Hospice New Zealand and the Australia and New Zealand Society for Palliative Medicine (ANZSPM).

Public information specific to each DHB area is necessary to:

- outline the public's rights/entitlement to palliative care services
- describe the services offered by palliative care providers
- provide information on what the public should expect from a palliative care service.

Strategy 7:
Develop the palliative care workforce and training

In order to develop the palliative care workforce and training requirements the following need to occur.

- Workforce and education requirements for specialist and local palliative care services need to be determined. This should include work to determine the numbers of Māori care co-ordinators and Māori palliative care health professionals that are required.
- The Medical and Nursing Council should be asked to:
  - provide guidelines to medical and nursing schools on the minimum content of palliative care training at the undergraduate level
  - take account of future nurse prescribing in postgraduate palliative care courses.
- Schools of Medicine should be requested to implement the Australasian medical undergraduate palliative care curriculum.
- The Clinical Training Agency should be requested to work in conjunction with educational bodies and professional organisations (for example, Hospice New Zealand) to determine the gaps in postgraduate palliative care training and identify what the clinical training needs are for palliative care and what can be provided through the Clinical Training Agency.
- Palliative care services should be asked to provide induction and ongoing training for volunteers. A national course has been developed by Hospice New Zealand.

Strategy 8:
Ensure that recommendations from the Paediatric Review are implemented

This strategy supports the implementation of the *Paediatric Review* recommendations.

It is recommended that the Ministry of Health in conjunction with DHBs work with hospitals to:

- identify and implement the national children's palliative care team
- develop and implement the local paediatric palliative care co-ordination service.

DHBs will need to review existing hospital funding sources and implement the children's palliative care service in line with the available budget.

Strategy 9:
Address issues of income support

A significant financial burden can be placed on people who are dying and on their families. It is important that criteria for accessing income support can take into consideration individual circumstances. In resolving issues relating to accessing income support it is recommended that a working party comprising the Ministry of Health, the Department of Work and Income and relevant providers be established.

To avoid duplication of work this working party should also address other income support issues that have arisen through other strategy work; for example, the national transport and accommodation policy and the Health of Older People Strategy.

Appendix 1:
New Zealand Work on Palliative Care

In recognition that limited central planning of palliative care services had been undertaken by the Government, the Core Health and Disability Support Services Committee undertook work in 1992 on palliative care service provision. The report recommended that hospice services be given priority by regional health authorities over the following two years.

As a result, a number of agencies in New Zealand undertook work in palliative care. This work focused on identifying the issues and problems in palliative care provision (Barnett and Smith 1992; Ministry of Health 1993, 1998; Robertshaw 1994; Penny 1997).

More recently, the National Health Committee and the HFA have undertaken significant work in the palliative care area.

The National Health Committee project: 'Care of the Dying'

This work was conducted over a two-year period beginning in January 1997. The aim was to 'provide clear specifications of services that should be available to people who are dying, settings in which it would be most appropriate for these to be provided and the service providers who would be available to provide them'.

The Committee was also charged with reviewing primary and secondary care involvement, workforce development needs, the impact of changing demographics, conditions appropriate for palliative care and changing expectations of access to services.

The project was overseen by an advisory group, and areas of particular interest were addressed by five working parties. These covered:

- service specifications
- best practice
- ethical/legal issues
- decision-making
- Māori issues.

The following recommendations were agreed as part of this work.

Recommendation 1

All people should have access to core health and support services appropriate to their needs.

Recommendation 2

Services for the care of people who are dying should be fully integrated into and recognised as an essential part of the wider sector of publicly funded health and disability services.

- The contribution of volunteers should be recognised and the cost of volunteer deployment included in funding provision.
- Pilots should be established to assess the effectiveness and practicability of integrated palliative care services.

Recommendation 3

Medical and other health professionals should inform patients and their family/whānau about palliative care and continuing support as an option for clinical management at the end of life.

- Health professionals, especially doctors and nurses, should be adequately trained in communicating with patients and their family about the goals of care. They should be able to offer advanced care planning, including palliative care, as an option to active treatment.
- Health professionals should be trained at an undergraduate level in the basic principles of palliative care and be able to make timely and appropriate referrals to palliative care services when this is clinically indicated and in line with patients' preferences.
- Clinical pathways and clinical guidelines on the management of specific conditions should include guidance on when treatment might be considered futile, and the palliative care option should be discussed with patients.
- Guidance should be available to clinicians dealing with cases in which rationing decisions result in the palliative care option being pursued.
- The professional colleges should encourage postgraduate training for doctors and nurses in managing patients at the end of life and counselling patients about the goals of treatment, the relative risks, benefits, etc.
- Health professionals should encourage patients to anticipate their health care needs and express their preferences for a time at some future date when they may no longer be mentally competent to do so.
- Treatment should reflect a shared understanding among health professionals of patient preferences for the goals of care.
- Acute palliative care intervention, consultation and referral for ongoing management should be available in all secondary care facilities.
- Enhanced communication between health professionals and their patients/families is preferable to increased use of advanced directives.

Recommendation 4

Education of health professionals and volunteers should promote attitudes and behaviours that respond to the needs of people who are dying and their family/whānau.

- The ANZSPM undergraduate medical palliative care curriculum should be adopted by the medical schools in New Zealand, and palliative care should be approached in a systematic way throughout the undergraduate years.
- Specialist palliative care providers should be actively involved in the planning and implementation of appropriate continuing medical education.
- Schools of nursing should access palliative care resources to facilitate student preparation for care of the dying.
- Funding should be available for postgraduate palliative care nursing education and continuation of the delivery of the Hospice New Zealand modules.
- The role of the volunteer should be recognised, with volunteer education included in service provision funding.
- The HFA/Ministry of Health should purchase a health promotion strategy, including information for people facing a life-threatening illness, health care providers, churches, marae and other voluntary helping agencies, and a media strategy aimed at increasing public awareness and understanding of issues related to palliative care.

Recommendation 5

Services need to address the specific needs of Māori.

Recommendation 6

Patients who are dying should receive adequate pain control. The law should be amended to enable people to appoint others to make a greater range of decisions on their behalf if they become incapable of making them for themselves.

Relevant work undertaken by the HFA

In 1998 the HFA, in conjunction with Hospice New Zealand, initiated the development of a national purchasing strategy for palliative care. This was halted in March 1999 to enable the HFA to undertake interim work that addressed the particular funding difficulties of some hospices.

This interim work produced information that was then provided to the HFA's localities for funding consideration in the 1999/2000 year. In many cases adjustments were made to the funding levels of hospices as an interim measure while the national work was being completed. The strategy was then resumed in conjunction with the Ministry of Health.

Appendix 2: Advisory Group Members and Terms of Reference

Terms of reference

1. Provide expert advice on the current provision of palliative care to the Ministry of Health, National Health Committee and HFA project team. This may include but is not limited to advice related to:
    - how the current provision of palliative care can be improved
    - improving integration of palliative care services
    - improving boundaries of palliative care services
    - removal of gaps in the provision of palliative care and improving access to palliative care services
    - improving quality/monitoring of palliative care services
    - workforce issues associated with palliative care
    - improving equity of funding of palliative care.
2. Review documents/information during the development of the national palliative care strategy and purchasing project.
3. Provide expert advice to the project team on strategy options for the provision and funding of palliative care in New Zealand prior to consultation.
4. Provide expert advice to the project team on the results of consultation on the national strategy and purchasing options for palliative care in New Zealand.

Membership of the Advisory Group

Dr Rod MacLeod	Director of Palliative Care, Mary Potter Hospice
Ms Jan Nichols	Manager, St Josephs Hospice
Ms Robin Stead	Manager, Health Waikato
Ms Janice Wenn	Manager, Whaiora Whanui, Masterton
Dr Mark Jeffery	Oncologist with Canterbury Health
Ms Maggie Barry	Consumer representative; former Chair of the National Health Committee palliative care project
Dr Brian King	GP, Wellington City, with an interest in AIDS/HIV; member of AMTAC; formerly at Mary Potter Hospice
Mr Mervyn Monk	President of Hospice New Zealand; Manager Arohanui Hospice

Appendix 3:
People/Organisations Who Made Submissions or Attended Public Meetings on the Discussion Document

This list includes those members of the reference group who made submissions.

Names 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, Kaitaita
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
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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, Whakatanae
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, University of Auckland, Auckland
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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

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Ron McInnes, Manager, Hibiscus Coast Hospice, Whangaparoa 1463

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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

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Reverend Theo Carpenter, Health Committee, Kapiti Coast Grey Power Association Inc, Paraparaumu

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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

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Capital Coast Health Ltd, Wellington

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Janice Donaldson, Manager, Ngai Tahu Development Corp, Christchurch

Shona Lawson, Women's Health Action, Newmarket, Auckland

Age Concern, Wellington

Peter Woolford, General Practitioner, New Lynn Medical Centre, New Lynn, Auckland

Ministerial Advisory Council for Senior Citizens, Wellington

Names of attendees at meetings

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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 (HFA).

Auckland

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), Noelene 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 (HFA), Wendy Cook (HFA), Tearoha Rahui (HFA).

Hamilton

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 Hanson, Chris Page (Trevelyn Resthome), Valda Mehrtens (Trevelyn Resthome), Robyn Segedin (One Health Waikato), Des Swanelvelder (Health Waikato), Lyn Littlo (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 Grennell (Waikato Hospital), Rangi Komene (Health Waikato), Harata Baucke (Health Waikato), Julie Biengen (Health Waikato), Glennis Retemeyer (Raukawa Development Trust), Laura Lambie and Elizabeth Bang (HFA).

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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

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Otago

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Māori Focus Group, Porirua

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Carer Focus Group, Dunedin

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

General Practitioner Focus Group

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 (Ministry of Health).

Appendix 4: Overview of Palliative Care Services

This appendix provides demographic information and identifies the need for palliative care, describes palliative care services provided from 1998–99, and describes the workforce currently caring for people who are dying.

Demographic trends: identifying the need for palliative care services

Causes of death

Table A1 shows the age-standardised death rates for selected causes of death in 1996. The leading causes of death in 1996 were cancer and ischaemic heart disease. Cancer has been the leading cause of death since 1993, accounting for around 26 percent of all deaths per year.

Table A1: Causes of death, 1996

Cause of death	Rates per 100,000 population[1]
All causes of death	493.3
Total cancer	140.0
Ischaemic heart disease	106.1
Cerebrovascular disease	38.1
Hypertensive disease	4.4
Other forms of heart disease[2]	19.5
CORD[3]	19.5
Pneumonia and influenza	15.8
Diabetes mellitus	10.5
HIV	0.9

[1] Age-standardised to Segi's world population.

[2] Includes heart failure, cardiomyopathy, pericardial and endocardial diseases.

[3] Chronic obstructive respiratory disease.

Determining the need for palliative care

The need for palliative care services can be estimated from cancer statistics and statistics of end-stage non-malignant disease (Higginson 1996).

Cancer

People who are dying of cancer often have physical, psychological and spiritual needs appropriate to palliative care. The greatest need for palliative care will be from people with cancer aged 60 and over. In 1996 there were 7461 deaths from cancer and 78.8 percent (5879) of these deaths were people aged 60 and over. Māori cancer deaths accounted for 8.6 percent of cancer deaths.

Between the periods 1997 to 2001 and 2007 to 2011 we can expect the number of people dying from cancer to increase by approximately 24 percent (Cox 1995); this is probably due mainly to the aging population.

Utilising overseas research (Higginson 1996) it can be estimated that around 84 percent of people dying of cancer will experience pain that may need palliation. Using the 1996 mortality data, this would work out to be 6267 people.

Data collected from hospices in 1998/99 indicate hospice providers cared for 4886 people who were dying; approximately 90 percent of these people died from cancer. Using the above estimate of those requiring palliative care services, this would suggest that approximately 1800 people who are dying from cancer are either not receiving palliative care or are receiving palliative care by other providers. These are likely to be hospital providers (see Table A2).

Non-malignant diseases

Overseas experience indicates that there is an increasing need for palliative care services for those with non-malignant diagnoses (Kite et al 1999; Higginson 1998). Estimates of the number of cancer deaths range from 20 to 100 percent (Higginson 1996; APMGBI 2000). Those needing palliative care may have diseases such as ischaemic heart disease (the second highest cause of death), or disabling diseases such as motor neurone disease and multiple sclerosis, which often require palliative care in the terminal phase. Currently approximately 10 percent (489) of people with non-malignant disease access hospice services (HFA 1999).

Children

Although cancer is a leading cause of deaths in New Zealand adults, in 1996 it was responsible for only 40 (18.3 percent) of the 635 deaths in children aged 0–14. The majority of children's deaths (417) are in the first year of life and are mainly from respiratory infections, sudden infant death syndrome, congenital abnormalities and accidents. The remaining group (178) can have a wide range of diseases which are often rare, some of which can have a long terminal phase and require palliative care that is developmentally appropriate.

In considering children's palliative care needs it is important to note that children who are dying are mainly cared for at home. Some dying children may require hospital paediatric care and less than 1 percent of children who are dying are cared for in a hospice (HFA 1999). Their palliative care needs differ from adults' needs.

Place of death

Table A2 shows the place of death for New Zealanders (hospices are included in the private hospital statistics along with institutions such as rest homes). The table shows that overall a higher proportion of people with cancer and non-cancer diseases died in hospital than died at home. Fifty-three percent (340) of Māori people with cancer die at home; this is higher than the proportion of non-Māori people. Pacific peoples have almost as high a proportion of home deaths as Māori.

Overseas research supports the view that people prefer to die at home. Research by Higginson (1998) shows that 50–70 percent of people would prefer to have the choice of home care.

It is important in the planning of New Zealand palliative care services to ensure that sufficient palliative care services and community support are available if this is what people want.

Table A2: Place of death, by ethnicity, 1996

Place of death	Cancer deaths 1996 (%)			Non-cancer deaths 1996 (%)		
	Māori (n = 639)	Other (n = 6651)	Pacific peoples (n = 171)	Māori (n = 1991)	Other (n = 18,362)	Pacific peoples (n = 565)
Public hospital	35.5	39.0	42.1	39.2	41.3	45.7
Private residence	53.2	30.8	41.5	41.0	23.8	38.6
Private hospital or other institution	8.5	29.4	16.4	5.6	29.4	7.9
Psychiatric hospital	0.0	0.1	0.0	0.1	0.3	0.0
Other	2.8	0.6	0.0	14.3	5.2	7.8
Total	100	100	100	100	100	100

Service provision

This section provides information on palliative care service provision from 1998 to 1999. Dying people can receive services from a wide range of providers, including hospices, hospitals, community health services, GPs, rest homes, private hospitals, home support agencies, individual carer support providers and volunteers, but access is dependent on the availability of services.

Hospices

Geographical distribution of hospices in New Zealand

Hospices are distributed across the North Island and down the East Coast of the South Island. There are no hospices on the West Coast of the South Island, nor in particular areas such as the East Coast of the North Island, Wairau and Queenstown. The services provided by hospices vary across the country: five are voluntary-based services and employ no clinical staff. Voluntary hospices are situated in Kaipara,[2] Auckland, Tokoroa, Taupo and Oamaru. Where there are no hospices, hospitals and/or primary care providers provide care for dying people. Clearly, not all New Zealanders have access to the 37 hospice palliative care services currently available.

Service provision in hospices

In 1998/99 hospices cared for 4886 people, 80 percent of whom were 60 years and over (HFA 1999). Hospices are mainly free-standing units that provide dedicated palliative care to dying people in line with the World Health Organization philosophy of palliative care (WHO 1990). Care is mainly delivered to people in their home.

Hospices may provide inpatient care, domiciliary (medical and nursing) care, day care, respite care and bereavement and counselling (Table A3). No hospice provides the full range of services (HFA 1999). Over half provide inpatient care, which is generally required for short admissions for symptom control and respite care, although some may use rest homes for respite care. Only a third of hospices provide night carer relief for patients,[3] while a large proportion provide bereavement counselling.

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[2] Kaipara now employs a full-time palliative care nurse co-ordinator.

[3] The Cancer Society can provide night carer relief in certain areas but only for cancer patients. The provision of night carer relief is dependent upon each particular division.

Table A3: Hospice services in New Zealand, 1998–99

Type of service	Number of hospices providing this service	Percentage of hospices providing this service
Inpatient care	19	59
Night carer relief	11	34
Medical advisory service	15	47
Nursing advisory service	21	66
Domiciliary palliative care nursing	19	59
Bereavement counselling	27	84
Spiritual care	18	56
Social work service	9	28
Day-care programme	22	69

Note: n = 32.

Hospitals

Service provision in Hospital and Health Services (HHSs)

Hospital services are particularly important where there are no hospice services, such as on the West Coast and in Central Otago. Each hospital has a number of facilities that provide services in outlying areas; for example, community and sub-acute hospitals.

Hospitals mainly provide services to dying people as a component of other services (for example, acute care or general care). This is generally not tailored for dying people. Inpatient care is mainly provided through general medical/surgical, oncology and older people wards. Community nursing care is provided through district nursing services. Allied health professionals provide some other services, such as social work services.

Information gained from HHSs is summarised in Table A4 and indicates that:

- the bulk of hospital service delivery for people who are dying is by district nurses through community health services
- dedicated beds for dying patients are provided in only 27 percent of hospitals – availability of other beds is dependent on demand for beds in any particular hospital
- there are hospital palliative care teams in four hospitals – Auckland Hospital, Waikato Hospital, Wellington Hospital and Christchurch Hospital
- in addition to the three hospitals above, Starship Hospital provides a children's palliative care service.

Table A4: Percentage of Hospital and Health Services and hospices providing palliative care type services as reported by providers, 1998–99

Type of service	Number HHSs providing this service	Percentage of HHSs providing this service
Inpatient care	6	27
Night carer relief	7	32
Specialist palliative care hospital teams	3	14
District nursing	20	91
Bereavement counselling	12	55
Spiritual care	18	82
Social work service	21	95
Day care programme	0	0

Note: n = 22.

Availability of beds in hospices and hospitals

Table A5 shows that the majority of dedicated palliative care beds (85 percent) are provided by hospices. The total availability of beds in each locality has been calculated to provide an indication of where dedicated beds for dying patients are lacking. The table shows that beds in each locality range between 0.64 per 100,000 (Waikato) and 7.73 per 100,000 in Wellington. Britain has an average of 5.1 palliative care beds per 100,000 (Eve et al 1997). If Britain is used as a comparison, Auckland, Waikato, Bay of Plenty and Nelson/Marlborough would appear under-resourced in terms of dedicated beds, although there may be (less appropriate) access to acute beds in general medical/surgical and oncology wards, or in assessment, treatment and rehabilitation units. In some areas (for example, Waikato where there are a low number of beds) hospices may use rest home beds for people who are dying.

Table A5: Palliative care beds, by type, locality and location, 1998–99

Locality	Dedicated beds in an acute hospital	Hospice beds	Total beds for region	Beds/100,000 populationin
Northland	1	5	6	4.38
Auckland	4	36[1]	40	3.70
Waikato	2		2	0.64
Bay of Plenty	2		2	0.77
Taranaki		6[2]	6	5.62
Tarawhiti/Hawke's Bay	2	8[3]	10	5.28
Wanganui/Manawatu		13	13	5.96
Wellington		32	32	7.73
Nelson/Marlborough		0[4]	0	0.0
Canterbury/West Coast	5	16	21	4.21
Otago/Southland		14	14	4.93
Total	16	130	146	4.03

[1] Excludes 3 rest home beds subcontracted to a rest home by West Auckland Hospice, but includes 6 beds at the Auckland City Mission that are for HIV/AIDS patients.

[2] Six beds are sub-contracted to Taranaki Hospice by Taranaki Healthcare Ltd.

[3] Including 2 beds at the Rollinson Unit (Napier Hospital).

[4] During the data collection, Nelson hospice was a community-based service with no beds. It now has 4 beds, which gives Nelson/Marlborough 3.34 beds/100,000.

Primary care service provision

GPs and primary health care nurses generally provide care for dying people in the surgery or through home visits, in addition to care provided by a hospice or hospital if geographically accessible. GPs may also be employed by hospices to provide medical care.

While varying in scope between individual practitioners, primary care provision has an important role in ensuring continuity of care for dying people and in facilitating relevant access to hospital and hospice services.

Carer support and residential care

People who are dying and their families may access disability support service (DSS) managed carer services, provided either at home or in a provider setting, usually for 28 days. The person can choose to use their carer support allocation for night carer relief. The criteria and methods for access to carer support vary between regions.

Dying people who cannot access community support or who require longer-term inpatient care than that provided by hospitals or hospices sometimes access residential care through DSS, most often through services for older people. Access to this service is also variable across the country. All people accessing DSS-funded residential care and who meet the Ministry definition of disability must go through a needs assessment/service co-ordination process (NASC). Outside of the DSS process dying people can either:

- access residential care via a NASC agency without going through a formal needs assessment process; or
- access care by referral from a hospital department or a GP.

Some people will already be in a residential setting and either develop a terminal illness or have their illness become terminal (for example, those who develop cancer or end-stage motor neurone disease). These people are likely to stay in the residential setting and will need to access palliative care services.

The quality of residential palliative care is dependent on staffing levels, numbers of registered personnel and the amount of palliative care experience within the institution. Some hospices have formal links with certain rest homes and provide education on palliative care.

Voluntary services

There are a number of voluntary organisations that provide care to dying people, such as the Cancer Society, which offers counselling, and some support services for people with cancer. In some areas in New Zealand they also fund night carer relief services. However, volunteers working for hospices, form the largest group of voluntary support. Table A6 shows that in 1998/99 volunteers gave 322,672 hours.

Palliative care service provision for children

Much work in identifying palliative care services available for children has already been completed by the *Paediatric Review* (Ministry of Health 1998). The review identified that palliative care services for children are delivered mainly by oncology units, local specialist child health teams and primary care providers in conjunction with DSS, voluntary agencies and other groups, including paediatric specialists.

In response to the review, a children's palliative care team has been introduced into Starship Hospital. The team has been active for over a year and includes a full-time palliative care nurse specialist, two part-time social workers and a child psychotherapist. It provides a regional service in the Auckland area and advice on palliative care nationally.

Funding of services

Hospices

Funding for hospices varies between regions. For example, hospices in the central region have in the past been funded on a per patient basis while hospices in the southern region were mainly funded on numbers of bed days. At the time of this research, hospices were partially funded by the Government to approximately 50 percent of their operating costs. This percentage is increasing. The balance is raised through fundraising and voluntary donations.

Hospitals

All hospital services are funded by the Government to provide free care. The cost of domiciliary services is funded by the volumes of community district nurse visits. The funding of inpatient palliative care is not explicit and is generally funded by case weights (case mix) through a number of contract lines, including general medical/surgical, oncology and older people.

Primary care services

The funding for palliative primary care services is similar to that for other primary care services. Depending on whether people have a Community Services or High User Health Card they pay either a full or part charge for the service provided.

Carer support and residential care

Funding of carer support and residential care is mainly through DSS. People receiving carer support services are not income and asset tested.

If a person with an age-related disability requires aged-care residential services they may be income and asset tested by the Department of Work and Income, in which case they may be required to contribute towards the cost of their care. Anecdotal evidence suggests that some people receiving residential care to meet their palliative care need may also be undergoing income and asset testing as if they had an age-related disability. In other situations, people needing palliative care may be bypassing the income and asset testing process altogether, with either themselves or their family funding their residential care. In regions where there is funding available for palliative residential care, this service is usually fully funded (for example, Wellington) for those people who meet the criteria, and the income and asset testing regime does not apply.

Palliative care workforce and training

Workforce and training issues are an integral part of planning for palliative care services and ensuring that quality palliative care services are available. Table A6 provides a summary of the palliative care workforce.

Table A6: Summary of hospice and hospital workforce, 1998–99 (FTE)

Workforce	Hospice	Hospital
Palliative care specialists	8.9	3.2
Other medical doctors	15.5 Mainly provided by GPs	Provided by oncologists, physicians, geriatricians
Hospital palliative care nurses*	–	5
Palliative care nurses	116.2	Provided by district nurses. Approximately 50 percent of district nursing services have one or more district nurses with palliative care training.
Registered and enrolled nurses	106.1	
Counsellors	14.1	As part of generalist services
Chaplains	3.8	As part of generalist services
Other allied health professionals**	9.4	As part of generalist services
Volunteers	322,672 hours	

Source of data: HFA 1999

*Acting in a nurse consultant role.

** Includes social workers (2.5 FTE), pharmacists (1.4 FTE), physiotherapists (1.1 FTE) and occupational therapists (4.4 FTE).

The key findings from the workforce data are as follows.

- 8.9 FTE palliative care medicine specialists were employed by hospices during 1998–99.[4] A number of these specialists worked part-time and were situated in Auckland, Waikato, Taranaki, Wanganui/ Manawatu, Wellington, Christchurch and Otago. The largest number were employed in Wellington (3.3 FTE). Where there is no palliative care medicine specialist available, a GP or other doctor (for example, an anaesthetist) provided medical care.
- 3.2 FTE palliative medicine specialists were employed in hospitals during 1998–99, yet approximately 40 percent of cancer and non-cancer deaths occur in hospital (see earlier). Inpatient medical care to dying patients in hospitals is mainly provided by oncologists, physicians and geriatricians.

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[4] Since this research approximately 12 additional doctors have completed the chapter of palliative care medicine (FAChPM). However, only a few of these doctors would currently be working in palliative care services. They are mainly working in general services.

- Just over half of the hospice nursing workforce have some training in palliative care. There is no clear definition of a specialist palliative care nurse. Few palliative care nurses have specialist qualifications beyond a graduate certificate level.
- Registered nurses in hospitals with palliative care training/experience are generally employed either in a hospital palliative care team or as a district nurse. Approximately half of the district nursing services had one or more district nurses who have completed some training in palliative care.
- Although allied health professionals are seen as part of the multidisciplinary team, there were very few working solely in palliative care. Few allied health professionals hold appropriate postgraduate palliative care qualifications.
- Volunteers make up a large part of the hospice workforce. Volunteers donated a total of 322,672 hours to the national hospice workforce during 1998–99: inpatient care 19 percent, administration 32 percent, community 12 percent, and fundraising 37 percent.

Training of the palliative care workforce

Both undergraduate and postgraduate education of the workforce is important in the provision of quality palliative care. Currently, undergraduate education provides only a limited amount of training in palliative care, and workforce data indicates there is a need for more at the postgraduate level.

Postgraduate courses available for health professionals who work in palliative care include:

- Royal College of Physicians' education for doctors becoming a palliative care medicine specialist
- Hospice New Zealand graduate certificate in palliative care for all health professionals
- some nursing master's programmes offer education in palliative care
- overseas programmes (for example, through Flinders University in Australia).

The Goodfellow Unit at Auckland University is currently proposing a six-month certificate and a one-year diploma in palliative care

Volunteers tend to undergo a variety of education programmes depending on the particular hospice. There is a need to determine the required level/standard training of health professionals and volunteers who are providing palliative care services in New Zealand. This would include determining the standards/training needs of Māori.

Future workforce and training requirements

It is difficult to estimate future workforce and training requirements in the context of an evolving palliative care service.

The Association for Palliative Medicine of Great Britain and Ireland has attempted to estimate the number of palliative care medicine specialists required for Britain. The methodology is based on numbers of cancer and non-cancer deaths, the proportion likely to use palliative care medicine specialists, and numbers of new referrals seen by specialists. Using this methodology it can be estimated that 17.4 FTE palliative care medicine specialists would be required for the New Zealand setting – 8.5 FTE more than was available in 1998–99. With the chapter in palliative care medicine (FAChPM) available it is expected that by the year 2001 there will be approximately 25 doctors with qualifications in palliative care.

This information needs to be considered alongside other palliative care workforce needs, geographical factors and the future direction of palliative care services in New Zealand, while encompassing the changing workforce. When proposed legislation enables nurse prescribing for the child and family and older people, palliative care nurses will be offered an additional one-year training course (at master's level) in prescribing. The ability to prescribe to dying people would have implications for the future palliative care workforce and delivery of palliative care services, in rural areas for example.

Appendix 5: Issues Relating to Palliative Care Services in New Zealand

A range of issues and areas of concern currently face palliative care service provision in New Zealand.[5] These include:

1. a lack of a palliative care approach in some services
2. variable access to palliative care services
3. lack of integration and inflexibility of palliative care services
4. a lack of standard quality specifications or performance indicators/outcome measures
5. a lack of workforce planning for palliative care
6. variability in the funding of palliative care services.

Issue 1:
Lack of a palliative care approach

Hospitals have a strong curative, intervention-focused culture, and with 39 percent of cancer deaths occurring in public hospitals it appears likely that the palliative approach may be lacking in the hospital environment. There also appears to be scanty provision of palliative care in institutional settings for the care of older people and those with degenerative conditions.

A recent study by Christakis and Lamont (2000) identified that doctors tended to overestimate a patient's survival by a factor of 5.3. This degree of overestimation may adversely affect the quality of life of patients. There is also a perception by some health professionals that palliative care is only for those people who are 'imminently dying'; that is, within a matter of days or weeks, when in reality palliative care can be provided for up to 12 months before death.

The National Health Committee noted that too frequently people continue to receive inappropriate levels of intervention when they would have been better served by a palliative approach. The normality of death as a process in life's cycle is in danger of becoming 'medicalised' (Smith 2000).

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[5] See also consultation analysis available on the Ministry of Health Web site.

Issue 2:
Access to palliative care services

Service gaps and national variation in different aspects of care

A number of service gaps have been identified in New Zealand (HFA 1999). This is consistent with findings overseas (Doyle 1990; Hatcliffe and Smith 1997) and is to be expected given the recent ad hoc purchasing approaches and inconsistent development of palliative care services. Service gaps identified include the following.

Night carer relief

There is a lack of provision of appropriate night carer relief in all areas of New Zealand, sometimes resulting in hospital admission. Cancer Society financial assistance is not available nationally, nor for people with conditions other than cancer.

Community care to support people wishing to die at home

While some hospices, GPs and hospital nursing services provide some good community care services, nationally there is a lack of sufficient community care and social support to allow people to die at home. Further, while some people caring for a dying person can access the 28-day carer relief support through DSS, the amount of care provided can be dependent on a needs assessment. The current nature of a DSS needs assessment is often considered insufficient in determining the needs of people who are dying. Also, dying people requiring support care may be prevented from access to support services because they do not fit the definition of disability and therefore are not eligible for services funded by DSS.

Patients who do not have sufficient support at home may have to be admitted to a hospital, hospice or rest home.

Inpatient care

There is a large variation in the availability of palliative care beds in hospitals and hospices (HFA 1999). Many providers have advised that there are insufficient beds for palliative care, respite care and medium- to long-term care, and sometimes a lack of 24-hour and specialist palliative care.

Accessing long-term care is a significant issue. Long-term care is generally not provided by hospices or hospitals. By default, patients often have to access care via a rest home. This care may or may not be appropriate, depending on the rest home's staffing levels, expertise, and links with palliative care organisations. Rest homes may not be appropriate for younger people who require longer-term care. Additionally, there can often be a significant user charge involved in accessing rest home care. As in support care there is also an issue around people being denied access to these services because of interface and funding boundary issues between personal health services and DSS.

Palliative care in rural areas

While someone in a city area may have access to a wide range of quality services, people living in a rural area may have significantly reduced access. Providers have reported access problems in rural Northland, Waikato, Bay of Plenty, Taranaki, Nelson/ Marlborough, and the West Coast.[6] People dying in rural areas are generally dependent on GP, primary health care nurse and district nursing services, which are often in short supply.

Spiritual care or bereavement support in both hospices and hospitals

There is a need for people being cared for by community-based services to have access to appropriate spiritual and bereavement counselling. Current access to these services is not universal.

Information to patients and their families

There is insufficient information provided to patients who are dying and their family/whānau about treatment and palliation options and the services and providers available to meet their choices.

Access to palliative care for people with non-malignant disease

People with end-stage non-malignant disease (for example, those with congestive heart failure, chronic obstructive respiratory disease, AIDS, motor neurone disease and multiple sclerosis) may not be viewed as having a 'terminal' illness in the same way as someone with cancer. These people do not always receive the same types or level of palliative care support (Mcilfatrick and Curran 1999), either because it is not available or because the need for palliative care has not been identified as an option.

This is also true for children. The Ministry of Health publication *Children and Young People with Terminal Illness* (1994) reports that resources available to this medically fragile group compare poorly with those available to clients with cancer. This is largely due to the public sympathy towards children with cancer.

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[6] Health Funding Authority Database 2000.

Māori access to palliative care

The following issues affecting access to palliative care services for Māori have been identified.[7]

- There is a lack of awareness about palliative care services among Māori and the options that can exist when a life-shortening illness is diagnosed. There also needs to be more information provided to whānau at the time of diagnosis with regard to the prognosis and time to death.
- There are no Māori palliative care provider organisations. Currently this type of care comes from mainstream services or through Māori providers with no specific education in palliative care. Training in palliative care is needed for Māori providers.
- There should be better co-ordination of services, particularly between mainstream and Māori providers.
- Over half (340) the Māori people with cancer die at home. This aspect needs to be considered when planning palliative care services for Māori.
- There is a need to ensure that mainstream providers understand the whānau model of health and illness and provide care in a culturally appropriate way. Clinicians in both hospices and hospitals do not always work with the wider whānau or Māori providers when co-ordinating care, yet the whānau is the main support for the Māori person who is dying.

Access to palliative care for children

The *Paediatric Review* found that while there was some provision of co-ordinated services (for example by oncology units), families may not be able to access the necessary palliative care services due to:

- poor co-ordination of current services and lack of a key co-ordinator
- a lack of appropriate needs assessment for families
- a lack of suitable respite care
- a lack of dedicated family support
- a total lack of co-ordinated grief and bereavement support and resources for this, mainly due to major deficiencies in the child mental health service
- a lack of resources and of a consistent network for provision of essential equipment and medication
- a lack of specific services for youth
- a high degree of variability in accessing the paediatric community or outreach nurse.

There is also a need for age-appropriate support for children whose parents are affected by terminal illness.

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[7] Issues identified by a Māori palliative care working party as part of this project and through work undertaken by the National Health Committee's work on Care of the Dying.

Access to palliative care for Pacific peoples

In general, Pacific peoples prefer to care for their dying family members at home. Pacific peoples have identified the following barriers to accessing palliative care (Care of the Dying Project).

- There are well-established cultural protocols for dealing with people who are dying, dictated by spiritual beliefs, but these are not always applied.
- There is philosophical opposition to the NFR (not for resuscitation policies).
- Pacific peoples often have difficulties accessing information about palliative care services. More information needs to be disseminated to Pacific peoples on the palliative care services that are available.
- There are often communication/language difficulties. This can mean that the disease and treatment process are not always explained adequately to the wider family group to enable them to make informed decisions. People may not understand the condition of their dying relative and this can influence access to necessary care.
- 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.
- There is a need to consider the specific needs of children within the context of the Pacific family.
- There is a need for palliative care services to understand Pacific cultures, especially in terms of the dying. In particular there is a need for hospitals to understand Pacific cultures better and when to introduce/refer people to palliative care services.
- Pacific peoples often prefer to manage on their own and may not ask for help.

Access to income support

There is an increased financial demand on families or the person who lives alone, either because they are no longer well enough to work or because they need to care for a partner or a child who is dying. For some it means there is no source of income while coping with the costs of caring for the one who is dying.

Rigidity in the rules that determine access to income support causes further financial stress. For example, there is generally a six-week to six-month stand-down period for people applying for the sickness, invalid or unemployment benefit. Social workers usually have to work with Department of Work and Income employees in manipulating rules to ensure that families have a source of income.

Failure to secure income can mean that the partner or parent cannot stop work to care for the dying adult or child who, perhaps denied the option of being cared for by family/whānau members, is admitted to hospital.

There is also a lack of support for families when institutional care is being provided. Home help is not available in this instance, although the spouse may be trying to balance children, work and visiting the patient.

Issue 3:
Lack of integration and inflexibility of services

While there are examples to the contrary, generally there appears to be little co-ordination or integration of services among providers (HFA 1999). There are also significant boundary issues impairing the delivery of seamless care (for example, in some places there are poor relationships between hospice staff and district and hospital nurses, and these are not helped by existing contracting mechanisms). Family members and people who are dying are reportedly having to navigate their own way through the different services, thus acting as the co-ordinators of their own care.

Lack of co-ordination and inflexibility of services can result in:

- people not being able to access the full range of palliative care services
- provision of inappropriate care (for example, hospital care when hospice or community care may be more appropriate and desirable)
- repeated acute admissions to hospital for some people in their last few months of life
- inefficient delivery of services (for example, some patients may be visited by more than four providers in a single day (HFA 1999))
- fragmentation and duplication of services
- an inability to provide flexible packages of care that are specific to an individual or their family's needs
- discrepancies in the services that are funded (for example, the medicines that are available and the extent to which they are funded vary between hospital and hospice environments and the community setting)
- older people and people living alone having problems accessing services.

Issue 4:
Quality of services and monitoring issues

Hospices and hospitals will be expected to meet the New Zealand Health and Safety Standards by 2002 once the legislation is passed. Draft documents have been developed for cancer and palliative care nurses to enable them to standardise the care they provide (for example, the Hospice New Zealand Guidelines for Hospice/Palliative Care Nurses and the NZNO Cancer Nurses Section – Standards of Practice).

However, the quality of palliative care service provision and the requirements for quality delivery vary considerably throughout the country.

- Standard quality specifications for palliative care services are only now being included in hospice contracts.

- While requirements for quality in hospitals and Independent Practitioner Associations are included in HFA contracts, these are very general and are not specific to palliative care.
- There is no specific monitoring framework to ensure that palliative care is being provided appropriately.
- Little or no information is collected for the purposes of benchmarking against other service providers.
- There is a lack of outcome measurements/performance measurements for palliative care.
- There are no guidelines for referral and best practice.
- There is a need for more research or the application of overseas research in palliative care:
  - so that palliative care is regarded as a credible alternative to other forms of treatment
  - to develop an evidence base that can influence practice
  - to provide assurance to consumers that services are safe and valid.

Issue 5:
Workforce and education

Issues relating to workforce and training also impact on the delivery and quality of palliative care services. These include:

- a need to develop national guidelines on palliative care workforce requirements to determine the appropriate number of staff that are required for palliative care services
- few palliative care medicine specialists working in palliative care services in New Zealand (8.9 in hospices and 3.2 in hospitals)
- few allied staff working solely in palliative care even though allied staff need to be part of a multidisciplinary team caring for the dying person
- anecdotal reports that volunteers are used inappropriately to deliver aspects of palliative care that should be undertaken by health professionals.
- lack of training in palliative care of allied workers (for example, home support workers and family members).

While there are a number of palliative care courses available in New Zealand, there is a need to:

- standardise education requirements for palliative care providers and the palliative care workforce in New Zealand (this includes training for volunteers)
- establish specific training in palliative care for undergraduate medical students: despite the approval by all the deans of the medical schools in Australia and New Zealand, the Australasian medical undergraduate palliative care curriculum has not been implemented
- develop undergraduate nursing education in palliative care further than the present minimal component.

Unless palliative care is given sufficient weight in the training of doctors and nurses it will be difficult to establish an enduring culture of palliative care or a palliative approach in the clinical setting.

Issue 6:
Funding of palliative care

Different regions receive different levels of funding (HFA 1999), with insufficient public funding available to fill the service gaps identified earlier.

Hospices are only partially government-funded and rely on bequests, donations and fundraising activities. Because of charities competing for fundraising it is becoming increasingly difficult for hospices to secure additional funds for what they regard as the provision of core services. At the same time they are seeing an increasing number of referred patients from hospitals and other services. Some hospices have advised that if further public funding is not made available, they will need to limit the range of services they provide.

Hospitals, some of which provide services additional to their contracted function, also indicate that they are under-funded for providing palliative care (HFA 1999).

GPs do not receive funding for service calls to dying patients. Many do not feel able to ask for reimbursement when making house calls for the terminally ill. In some circumstances, GPs who cannot continue to make house calls may then refer patients to hospital. Home visits can be carried out for a fraction of the cost of keeping a patient in a hospital bed (Survey of IPAs, Ministry of Health 1999). In recognition of this, some Independent Practitioner Association (for example, Southlink Health) have a capped palliative care budget from which GPs can claim to cover some of the costs of seeing terminally ill patients.

Appendix 6: Palliative Care in the United Kingdom, Australia and Canada

United Kingdom (UK)

The first hospices were developed in the UK in the 1960s, largely through voluntary effort. Although hospices in Britain have gained some government funding, they are still only partially government-funded and, like New Zealand, rely on fundraising activities and voluntary work.

In 1995 the National Council for Hospice and Specialist Palliative Care Service developed a model for palliative care in the UK which utilises existing services rather than continuing the proliferation of small hospice/palliative care units (NCHSPCS 1997). The model suggests that three to four models of palliative care provision need to develop in Britain, including:

- *community-based care,* using beds and bases mainly in the voluntary sector: consultants and nurses would come from a broadly based training background very much as at present
- *oncology centre exclusively for cancer patients:* care would start at an early stage and the medical team would have extensive training in oncology
- *hospital palliative care teams. Some may be provided from community bases in the National* Health Service, voluntary sector or via a partnership between the two. Many will be associated with the specialist care services linked to oncology services. Others will be separate hospital services available for patients with active, progressive and far-advanced disease, with or without a few designated beds in any ward or department. There would be a continuing trend for the acute hospital to create joint appointments with local voluntary hospices and specialist care units and jointly developed specialist clinics (for example, for chronic pain, lymphodema or rehabilitation of people with chronic diseases)
- *care exclusively for AIDS/HIV patients.*

Australia

Like Britain, the development of a tailored approach to palliative care has its roots in the voluntary sector through the hospice movement. The hospice palliative care service, supported by charity and government subsidies, was established in 1982. In 1988 Commonwealth funding was provided to the states and territories for palliative care under a 'Medicare Incentives Package'. The aim of this package was to support people with terminal illnesses in their own home and minimise hospitalisation where possible (Commonwealth 1998).

The provision of palliative care is variable across Australia with similar issues and problems as in New Zealand (Commonwealth 1998). This led to the development of a five-year national Strategy for Palliative Care in 1998 to provide guidance to governments and other service providers to undertake activities that aim to improve the quality, range and coverage of palliative care services. The Australian strategy addresses four areas for policy development, integration, access and equity, quality improvement, evaluation and education and information. An annual report is to be provided to the Health Minister (Commonwealth 1998).

Canada

Canadian palliative care programmes were first developed in 1974/75 and have sought to be integrated into mainstream health care at both institutional and community levels.[8] Palliative care is generally provided by an acute care inpatient unit that provides follow-up home care by nurses attached to the unit. A bereavement counselling service is also provided after death (Barnett and Smith 1992).

Various models of palliative care exist in Canada, including the Edmonton Regional Palliative Care Program, which provides an integrated programme of palliative care utilising hospice care, tertiary palliative care, and care by family physicians in the community (Bruera et al 1999). The Vancouver General Hospital Palliative Care Programme provides inpatient and community care, a consultancy service for other parts of the hospital and a bereavement follow-up programme (Tong 1993).

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[8] The Institute of Palliative Care, www.pallcare.org

Appendix 7: Explanation of Key Terms

Domiciliary or community palliative care nurses

These nurses provide care to people who are dying in the home or long-term residential facility. They generally work in a multidisciplinary team. The team may be attached to a general hospital with a cancer unit, inpatient hospice/palliative care unit or the community nursing service.

Hospice

The term hospice is used in two ways. It can refer to the philosophy and practice of hospice care, which is in effect the same as the philosophy and principles of palliative care in the definitions given in this document. It can also refer to a hospice unit. Usually this is a free-standing unit with inpatient facilities, where palliative care is practised, emphasising medical and psychosocial care. It usually has medical and nursing staff specially trained in palliative care and can offer day care, respite care and home support teams. Some hospices do not offer inpatient services.

Hospital palliative care teams

A hospital palliative care team provides palliative care within the acute hospital setting. The team has an advisory and education role and may provide direct care to patients and their families requiring a high level of palliative care skills. They also link people to services on discharge from hospital.

Inpatient care

The inpatient care given varies between service providers.

- Hospices provide inpatient care for the control of symptoms or for respite care. Some people may choose to die in a hospice. Inpatient care in hospices is generally for short stays of up to approximately 10 days.
- Hospitals provide inpatient care for acute care required by dying people. They can also provide care for symptom control and respite care, particularly where there are no hospices.
- Residential care mainly provides inpatient care for older people. However, dying people who can no longer stay at home but require care for a longer period than that provided by hospices or hospitals also access residential care.

Multidisciplinary team

This team would consist of a nurse, physician, social worker, physiotherapist, occupational therapist, pharmacist, bereavement counsellor, spiritual worker and dietician.

Night carer relief

Overnight nursing care for dying people to provide relief for families.

Palliative care services

A broad term that encompasses the provision of palliative care in both the home and inpatient setting by hospices, long-term residential care facilities and privately and publicly funded hospitals.

Palliative medicine

The study and management of people with advanced and progressive disease for whom the prognosis is limited and the focus of care is the quality of life. Palliative medicine includes consideration of the family's needs before and after the patient's death.

Quality of life

An individual's perception of their position in life in the context of the culture in which they live, and in relation to their goals, expectations and standards. The term incorporates concepts of physical and psychological wellbeing, levels of independence and autonomy, social relationships and support, and spirituality. Health-related quality of life emphasises the domains of physical and psychological wellbeing.

Rehabilitation

In the context of palliative care, rehabilitation refers to assisting dying people to achieve and maintain their maximum physical, emotional, spiritual, vocational and social potential in improving the quality of their remaining life.

Respite care

Respite care is essentially carer relief. In a model based on community care, respite care is fundamental for ensuring the family/carer is able to continue to care for the patient in the home. Respite care can take a number of forms and includes inpatient care provided by a hospice, hospital or rest home. Respite care can also include night carer relief, and other sitting-type services.

Specialist palliative care services

Palliative care services with palliative care as their core specialty. They require a high level of professional skills from trained staff. A significant minority of people whose deaths are anticipated need specialist palliative care services.

Terminal care

Usually refers to the management of patients during their last few days or weeks or even months of life from a point when it becomes clear that the patient is in a progressive state of decline.

Terminal illness

Active and progressive disease for which curative treatment is neither possible nor appropriate and from which death is certain. This varies from a few days to many months.

Terminal stage

Usually refers to a steady deterioration in the patient's condition, which indicates that death is close.

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"SMD-3"

From: Palliative Care Subcommittee, NZ Cancer Treatment Working Party
26 February 2007

New Zealand Palliative Care: A Working Definition.

1. Preamble

The NZ Palliative Care Strategy (2001) aims to set in place a systematic and informed approach to the provision and funding of palliative care services. Furthermore, any approach must address inequalities in palliative care. Current inequalities include access for Māori, Pacific peoples, isolated communities, children, the very old, those with non malignant disease, as well as those with special needs: asylum seekers/refugees, people in prison, and those with mental illness.

Fundamental to the strategy's success will be clarity around palliative care definitions. Definitions form the basis upon which a comprehensive, cohesive and effective palliative care service can be built and sustained. They help clarify core service components, elucidate structure, and promote understanding. They are also key components for national palliative care service specifications.

As a starting point for defining palliative care in a NZ context we have used the 2002 WHO palliative care definitions:

Palliative care: World Health Organisation Definition, 2002

For adults:

Palliative care is 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 early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patients' care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness

This is the exhibit marked "SMD-3" referred to in the
affidavit of Sinéad Marie Donnelly affirmed at
Wellington this 22 day of May 2015 before me:

Joyce Velasco
Deputy Registrar
~~A Solicitor~~ of the High Court of New Zealand
of Wellington

- Is applicable early in the course of the illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

For Children:

Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows (the principles also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease
- Health providers must evaluate and alleviate a child's physical, psychological and social distress
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited
- It can be provided in tertiary care facilities, in community health centres and even in children's homes

In applying the WHO definitions, New Zealand also needs to take into account the following :

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection. In addition, we must acknowledge and include He Korowai Oranga (the Māori Health Strategy (2002)). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Whā (four sided house) towards health/wellbeing is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau(family health).
2. Palliative care continues to evolve. Thus definitions need to be flexible enough to adapt to changes in society, disease and illness, and individual and society's expectations. Palliative care recognises and respects the rights of patients as detailed in the Code of Health and Disability Services Consumers' Rights.

3. Generalist Palliative Care will be available throughout the course of a life-limiting illness, with specialist palliative care provided on the basis of assessed need, rather than simply diagnosis or prognosis. Palliative care will also be available wherever the patient is – be that home, hospital, residential care, or hospice. Palliative care is centred on the patient and family / whānau. The level of palliative care support required for any individual, family or whānau is dynamic and varies during the course of illness (and into bereavement).

4. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whanau in contemporary New Zealand society.

5. Palliative care is best delivered through an integrated approach to care that recognises the roles and responsibilities of both palliative care generalists and specialists, in meeting palliative care need. This integrated model or framework of care delivery is essential for effective palliative care provision.

6. The patient's primary care team will continue to provide continuity of care through illness. Depending on need, the involvement of specialist palliative care may be episodic or continuous.

7. In the case of children and young people, palliative care will also be available on the basis of assessed need. Specialist palliative care will be provided in collaboration with formally trained or experienced paediatric healthcare professionals either community (eg GP, district nurse) or hospital based. In New Zealand, home is the preferred and usual location for palliative care for children and young people. It is recognised, however, that some children and young people spend long periods of time in tertiary hospitals far from the primary care team.

2. In Detail

Generalist palliative care is palliative care provided for those affected by life-limiting illness as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team. It is provided in the community by general practice teams, Maori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Some of the generalist providers, e.g. general practice teams, will have ongoing contact with a family throughout and following illness. Others, such as district nurses or ward nurses will have episodic contact, depending on the needs of the patient and family.

Providers of generalist palliative care will have defined links with (a) specialist palliative care team(s) for the purposes of support and advice or in order to refer patients with complex needs. They will also have access to palliative care education to support their practice.

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

Specialist palliative care may be provided by hospice or hospital based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by generalist providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways:

1. Directly – to provide direct management and support of patients and families/ whānau where more complex palliative care need exceeds the resources of the generalist provider. Specialist palliative care involvement with any patient and the family/ whānau can be continuous or episodic depending on the changing need.

Complex need in this context is defined as a level of need that exceeds the resources of the generalist team – this may be in any of the domains of care – physical, psychological, spiritual, etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the generalist provision of palliative care provision.

Generalist/Specialist Integration

Generalist and specialist services need to be part of an integrated framework of care provision which may be facilitated through local and regional networks, with defined formal linkages to key services including community primary care, local acute hospitals, regional cancer centres, and other regional palliative providers.

Depending on the complexity of palliative care need, smaller specialist palliative care services will at times require input from a more comprehensive service with greater specialist resources which may be geographically distant. This must be readily available through defined linkages and processes.

From: Palliative Care Subcommittee, NZ Cancer Treatment Working Party
26 February 2007

Therefore, the New Zealand definition of Palliative Care is:

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

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

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

It should be available wherever the person may be.

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

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

"SMD-4"

This is the exhibit marked "SMD-4" referred to in the affidavit of **Sinéad Marie Donnelly** affirmed at Wellington this day of May 2015 before me:

Joyce Velasco **Deputy Registrar**

A ~~Solicitor~~ of the High Court of ~~New Zealand~~ **of the High Court of Wellington**

PALLIATIVE CARE COUNCIL
OF NEW ZEALAND

The Palliative Care Council of New Zealand's Position on Euthanasia

June 2013

Introduction and Purpose

There is widespread debate in New Zealand society about euthanasia and physician assisted suicide, largely based around anecdotal stories of sub-optimal care at the end of life. The Palliative Care Council of New Zealand (the Council) is an independent body with a multi-disciplinary membership reporting to and providing strategic advice to the Minister of Health about palliative and end-of-life care.

A priority of the Council is to ensure that every person in New Zealand has access to quality palliative care, whenever and wherever it is needed. Palliative care is not only provided by specialist services such as hospices, but by health care professionals in a range of settings, including primary care, residential care facilities and hospitals. Palliative care providers must ensure that holistic and respectful care is always provided, that symptoms are managed adequately and family/whanau and carers are supported, wherever the dying person may be. This is essential if societal fears around care at the end of life are to be allayed.

Dignity in dying is a fundamental goal, something our patients are quite justified in expecting us to provide. Through work done at Starship Children's Health, Maori leadership offer us "Te Wa Aroha – Allow Natural Death". Te Wa Aroha means "a time of love" and focuses on what can and will be done at the end of life for individuals and their families, and that this time and care is as natural as possible. Terminology emphasises reducing suffering and promoting comfort, quality and dignity.

Despite on-going improvements in the availability and quality of palliative care, the debate around euthanasia will continue, especially given our ageing population. Conversations must focus not only on the wishes, fears and concerns of individuals but also what is right for the community. The Council recognises this dialogue is challenging, as views and opinions vary widely, both within the general public but also amongst health professionals.

This statement sets out the Council's position on this complex and emotive issue. Some relevant definitions are noted below:

> **Euthanasia** is the deliberate ending of another person's life at his or her request. It is generally performed with the intention of relieving "intractable suffering". If someone other than the person who dies performs the last act, euthanasia has occurred.
>
> **Physician assisted suicide (PAS)** is where a doctor intentionally helps a person to commit suicide by providing drugs (or other means) for self-administration, at the person's voluntary and competent request. If the person who dies performs the last act, physician-assisted suicide has occurred.

Palliative care is the care of people dying from active, progressive diseases or other conditions that are not responsive to curative treatment; providing relief from pain and other distressing symptoms. Palliative care embraces the physical, social, emotional and spiritual elements of wellbeing – tinana, whanau, hinengaro and wairua – and enhances a person's quality of life while they are dying. Palliative care integrates a multi-disciplinary team approach to address the needs of patients and their families/whanau, extending into the psychological and spiritual aspects of care and into the bereavement phase if required. Palliative care affirms life and regards dying as a normal process and intends neither to hasten nor postpone death.

Focussing on Palliative Care

The Palliative Care Council of New Zealand believes that dying is part of the experience of living and that no-one has to die in avoidable pain and suffering. All New Zealanders have the right to receive high quality palliative and end-of-life care regardless of ethnicity, age, geographic location or diagnosis.

Palliative care is appropriate for all people, not just those with cancer. It extends to anyone with any life-limiting illness or condition that would benefit, such as cardiac, respiratory, neurological, renal, vascular conditions, etc.

When requests for euthanasia or assisted suicide arise, particular attention should be given to good symptom control, especially those commonly associated with a serious and sustained "desire for death" such as depressive disorders and poorly controlled pain. In such situations early referral to an appropriate specialist should be considered.

The Palliative Care Council

- *strongly encourages* the concept of death with dignity and advocates that this be a high priority for health care in New Zealand;
- *acknowledges* it is not always possible to completely relieve suffering, but that good palliative care improves the experience of living with and dying of a terminal condition;
- *believes* that people have the absolute right to refuse life sustaining treatments including the provision of medically assisted nutrition and/or hydration, and that carrying out the person's wishes of refusal does **not** constitute euthanasia;
- *believes* that the benefits and harms of any treatments (including the provision of medically-assisted nutrition and/or hydration) should be considered before they are started and that the benefits and harms of continuing treatments should also be regularly reviewed. Stopping treatments that are not benefitting the patient is **not** euthanasia;
- *believes that* if treatment **appropriately** titrated to relieve symptoms has a secondary and unintended consequence of hastening death that this is **not** euthanasia;

- *advocates* that all patients should be made aware of the options for hospice and palliative care, with individual assessment of their needs to ensure appropriate palliative care is being provided;
- *believes* that euthanasia and physician assisted suicide do not have a place in New Zealand society; instead the focus should be on ensuring high quality palliative care is available to all who would benefit;
- *notes* that both euthanasia and assisted suicide are against the current ethical positions of the medical and nursing professions in New Zealand;
- *understands* the practices of euthanasia and physician assisted suicide to be illegal in New Zealand and that palliative care does not include the practice of either as there is a clear distinction between good care for the dying and active interventions instituted in order to deliberately end the life of a patient; and
- *acknowledges* that there are divergent views held by wider society about the ethics of euthanasia and physician assisted suicide and respects and upholds the rights of all to their own personal views.

The Palliative Care Council of New Zealand wishes to acknowledge the New Zealand Medical Association, Hospice New Zealand, the Australian & New Zealand Society of Palliative Medicine and the Palliative Care Nurses New Zealand Society. This position statement has been distilled from the work and words of all five organisations.

This statement is endorsed by Cancer Control New Zealand

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"I wouldn't want to become a nuisance under any circumstances"—a qualitative study of the reasons some healthy older individuals support medical practices that hasten death

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27th July 2012, Volume 125 Number 1358

Phillipa J Malpas, Kay Mitchell, Malcolm H Johnson

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Support for medical assistance in hastening death appears to be growing both around the world and in New Zealand. This is evidenced by the fact that in the past decade a number of countries and states have legislated for euthanasia and/or physician-assisted suicide to be made available to patients in carefully qualified situations (the Netherlands, Belgium, and Luxembourg)[1] .

Presently, the states of Oregon, Washington and Montana in the USA allow for physician-assisted suicide. Laws in Switzerland accommodate assisted suicide that does not necessarily involve assistance by a physician.

Over the past 2 decades a number of studies have examined the attitudes of terminally ill patients[2-5] and physicians[6-8] towards medical practices that hasten death (euthanasia and physician-assisted suicide). For instance, Wilson et al[9] found that psychological aspects may be as important as physical symptoms for cancer patients who would actually make a request for their death to be hastened by a physician.

Johansen and colleagues[10] also investigated attitudes towards physician-assisted dying with cancer patients who had a life expectancy of less than 9 months. They found that whilst some patients held positive attitudes towards euthanasia and physician-assisted suicide, the wish to die was ambivalent and fluctuating: a mental 'solution' for the future. Further studies have explored physicians' experiences of end of life decision-making[11-15].

Furthermore in New Zealand, two surveys of the general population concluded that around 70% of New Zealanders support medical assistance in hastening death when someone is terminally ill and their suffering is intractable and unbearable.[16,17] Some general practitioners in New Zealand consider it justifiable[18] and some do intentionally end the life of a patient who is incurably ill.[19]Despite this, practices that hasten a patient's dying are neither lawful[20] nor openly practised in New Zealand.

To date no study has explored the reasons healthy, older people might have for supporting medical practices that hasten death. Examining the reasons some individuals have for supporting these practices is important in understanding how individual circumstances may influence personal decisions concerning medical care and treatment at the end of life. For instance, in understanding the factors involved when requests are made to withdraw or withhold medical treatment, or in the preferences expressed in advance care directives.

Furthermore, exploring the preferences an individual has regarding end of life decision-making may help health practitioners develop more patient-centred care plans at the end of life.[21]

The present study set out to explore these reasons in the New Zealand context.

Methods

Study design and ethics—A qualitative approach was used to explore the reasons some older healthy individuals support medical practices that hasten death at the end of life.

This is the exhibit marked "SMD-5" referred to in the affidavit of Sinéad Marie Donnelly affirmed at Wellington this 12 day of May 2015 before me:

Deputy Registrar
of the High Court
at Wellington

Joyce Velasco
A Solicitor of the High Court of New Zealand

University of Auckland Human Participants Ethics Committee approval was obtained for the study (UAHPEC Reference number 2010/055).

Sample selection—Recruitment was from the Voluntary Euthanasia Society of New Zealand (VESNZ), an organisation that supports legal medical assistance in dying. All participants were members of VESNZ; some participants were also members of EXIT International. VESNZ Head Office forwarded 330 letters (from the researchers) advertising the study to Auckland members of the society inviting them to participate in the study. 138 people contacted PJM via phone, email or letter enquiring about the study.

All individuals who self-identified as healthy and were 65 years or older were sent information packs: these contained a participant information sheet explaining the study and what it entailed, a consent form, and a self-addressed envelope. 106 individuals returned signed consent forms which were numbered as they were opened. Every tenth participant was chosen for interviewing, with the exception of one spouse who was also interviewed (convenience sampling).Participants were then phoned by KM to ask about a convenient time to meet.

All interviews took place in the participant's home. After 11 interviews, saturation of information was reached and interviewing was stopped.

All participants lived in their own homes (one woman lived with her daughter), and all identified as healthy. None of the respondents had long term disabilities and were in fact remarkably healthy, except for an 89 year old woman who had mobility issues related to age-onset illness. This was not long-term, although she did not expect it to improve.

Participant numbers 4 and 4a were husband and wife.

Table 1. Demographic details of participants.

ID	Age	Gender	Religious affiliation	Living situation
1	79	female	No religious affiliation	Lives alone
2	78	male	Atheist	Lives alone
3	80	female	Baptist	Lives alone
4	82	male	No religious affiliation	Lives with wife
4a	86	female	No religious affiliation	Lives with husband
5	80	male	No religious affiliation	Lives with wife
6	88	female	No religious affiliation	Lives alone
7	89	female	Quaker	Lives with daughter
8	81	male	Atheist	Lives alone
9	69	male	Agnostic Christian	Lives with wife
10	75	male	No religious affiliation	Lives with partner

Data collection—Semi-structured interviews were conducted based on open questions concerning past experiences with death and dying, planning for end of life, concerns or fears about dying, reasons for joining VESNZ and/or EXIT. Interviews were conducted by one of the authors (KM) in respondent's homes, and took approximately 1 hour.

The phrase 'medical practices that hasten dying' referred to interventions by a doctor that either assisted a patient to die (as in giving the patient the means to end their own life at their explicit request—physician-assisted suicide), or directly ended a patient's life (as in a lethal medication administered by a doctor at the explicit request of the patient—euthanasia).

Interviews were recorded and transcribed. Each respondent was sent two copies of their transcript and asked to read and delete or alter any information they believed was inaccurate or did not represent their views. Once the transcripts were forwarded to the researchers they were used for purposes of analysis.

Analytical strategy—Our aim was to derive themes and meaning from the interviews. To do this we employed the grounded theory approach whereby responses in each previous interview were incorporated into the interview structure for subsequent interviews[22]. Interviews were imported into QSR NVivo 8 and subjected to multiple close readings by KM in a general inductive approach to identify broad categories of subject beneath which were identified themes that were coded for further analysis[23]. All three authors then separately read the interview sections and the final identification of themes and selection of representative quotations was by agreement.

Results

Participants' demographics–All participants were aged 65 years or older at the time of interview. Compared to the over 65s in the 2006 New Zealand Census, our sample were more likely to be European (100% cf 80.56%) and to have no religious affiliation (73% including atheists cf 11.8%).

Participants' responses—It became clear during the analysis that participants' reasons for supporting medical practices that hasten death were deeply intertwined and not easily captured in separate categories.

This can be seen in the interview with the first participant. She began by reflecting on caring for her mother more than 50 years ago when she was in her mid-20s and appears to incorporate this memory into her fears of being a burden on her own children:

> Although I didn't know it at the time she had cancer throughout her body [...]. I was the last one to get married so she lived with me. [...] It was a family responsibility
> I just feel that I don't want to be a burden on my children. And when I get old I don't want them to have to look after me. Um, it's just too hard for them, I don't want to do that to them

While the genesis of this fear of being a burden may have been in her memories of caring for her mother, it appears to have been awakened by a recent experience of visiting a friend with Parkinson's disease, in a rest home (nursing home):

> I have been to see them and those people; they are just waiting around to die. It's awful, it's just awful

Participants' reasons for supporting medical practices that hasten death at the end of life were clustered around four main categories: concern for self at the end of life, concern for others, prior observed experiences with health care, and suicide issues. The first three categories are the subject of this paper. Themes identified under these categories are reported in italics.

Concerns for self at the end of life—*The desire to remain independent* and active for as long as possible was raised by several participants in our study:

> Yeah. It's got to be an independent life, I mean I really don't think I want to live in a wheelchair in an institution you know (8)
> Oh God, I can't imagine not being independent (6)

A fear of pain and suffering at some future point in time was given as a reason for supporting assisted death, as was the need to maintain one's dignity at the end of life:

> My fear is pain and not being able to you know, live an independent life ...I certainly don't want to be incontinent lying in a hospital bed with no hope of ever getting better. Even if the pain could be dulled, it'd still be (8)
> That's the, that's the insidiousness of aging. I worked this out. I might have a small pain and I think oh, that's okay, I can live with it. And a week later it might be slightly worse and I think, oh, I can live with it. And a week later it will be slightly worse and then you go on and realise about a year later, you know, that life hasn't got much value because of the physical pain. And you just keep going on. Well I don't want to do that (1)

Autonomy was important to several participants who spoke strongly about their right to make their own decisions about what they wanted at the end of life, and less about the actual reality of what they could or could not accept:

> I cannot understand as I said right to start off with, why other people think they have got the right to tell me that I can't die when I want to and I don't see why I have to be desperately ill and talk to lord knows how many doctors to convince these people because I might not be in a state where I could convince anybody. All I know is that I know myself... Being in that sort of position and everybody's thinking that they're doing – they know better than we do and *'you shouldn't think like that dear'*, and all the rest of it. What the hell? I mean we've both gone 80, [...] we've got the right to clear off when we want to (4)
> I want to be aware enough to say 'no'. And I'd like to be able to do something about it while I have sufficient power (1)

Being useful appeared to be a bridge between concern for self and concern for others and was mentioned by several participants as a reason to go on living:

> Yes, I think it comes down to what I can contribute, how useful I am. And when I'm useless and have nothing to contribute and can't look after myself. I think that's when I would wish to do something about it (1)

One woman questioned whether she would be missed by her family if she suicided and then recalled how much her daily phone calls meant to her granddaughter and great granddaughter who lived overseas:

....my calls every day, I know she looks forward to them. I know she doesn't always speak [to me for long] but that's the only thing I might be, I feel, of some use. But then I'm not going to try to hang onto a life where there's nothing there. I mean that would be terrible (6)

Concerns for others—A negative alteration in mental and physical abilities and body image can lead to a negative concept of self.[24,25] Arguably in age, this is occurring at a time when a positive self-concept particularly in relation to loved ones becomes increasingly relevant to quality of life.

For many participants, the desire to be remembered 'in a good way' by loved ones is important. It was clear that individuals wanted others to remember them as someone who was both physically and psychologically healthy, and not as one who was now a shadow of their former self:

And I feel that when I get to that stage, I won't be like I am now. I won't be as they know me now, I will be somebody else who they, well they're sort of stuck with really (1)
I wouldn't want my grandchildren or daughters to see me at a stage when I am not the person that they always remember me as (5)

A desire not to be a drain on health care resources and society was articulated by several participants:

And I rather annoy I suppose a lot of my contemporaries because I really feel that, the old people around are a drain on resources. Well we are, it's a fact (6)

Being a burden or nuisance on others was a concern for a number of participants. It is a concern found in other studies:[26–28]

Knowing that you are a nuisance to everybody and getting little sympathy from caregivers frequently, um, even from family. You know you are a nuisance, a drag on them. I wouldn't want to become a nuisance under any circumstances (3)
Well if I was so physically handicapped that I couldn't do anything myself, if I needed attention all the time I would hate that. And um, and also if my mind was so unclear that I was just a trial. [...] Yes. Oh yes, I would hate to be a trial to people (7)

Becoming dependent on others for personal care and hygiene appearedrelated to being a burden, and troubled some individuals:

....if you couldn't do your basic care, couldn't wash yourself or go to the loo (toilet) by yourself, I don't want to go on after that. Thank you. And I don't expect (husband) wants me to go on like that either, or my family (4a)

One man spoke of his horror at the thought of having to be toileted:

When I can't wipe my own bum I want to be gone (2)

Prior observed experiences with health care—A number of participants began their interview discussing the decline and (in some cases) death of a family member or friend and how those experiences had influenced their views around the dying process.

The experience of seeing family members or friends in long term care also profoundly affected some participants. For some the experience happened several decades before.

One man said of his experience of visiting a long term care facility:

I've visited one of these old age peoples' places and oh what depressing places they are. I love organ music so I play the church organ. And I got dragged into going there one night and playing hymns for them and arrggh (expression of disgust). God, most of them had gone, you know (8)

The experience of witnessing the decline of friends and family involved issues around how pain and suffering was (mis)managed, the prolonged duration of an illness (such as Alzheimer's disease) and its effects on the family, having to do everything for another person, and concern about lack of dignity in dying. Some participants were adamant that as a result of their experiences, they did not want to move into long-term residential care.

Agich[29] notes that "in our culture it is less death than long-term care that strikes us as so repugnant". He argues that long term care has become associated with images of frailty and despair, loneliness and destitution. For some individuals in our study their prior experiences with long term care reinforced both their need to be self-reliant and independent for as long as possible, and their aversion to dependency and need.

My wife had an uncle who was just a couple of years older than her and he had a heart attack when he was about 40-something after we were married and he lost the power to move his arms and legs and would speak a little bit and effectively my wife looked after him for years and years and years and years.... and I used to go around there twice a week for half a day and do everything that he needed. And I just thought how horrible it would be in that state (5)

And my mother died at 90 and she had Alzheimer's [disease] for 20 years , and I'd go and see her every fortnight and my last remaining brother would do alternate weeks and we did that and it is very distressing to see that happen. And I'd hate to see me in similar circumstances (9)

I'm one of six brothers, four of whom have died. Three from cancer related illnesses and they died in their mid-50s, quite a short lifespan in my opinion and their passing, well their illness was quite devastating you know to witness what they had to go through and I thought well, if there was something I could have administered to stop their pain and suffering, I thought I would or I'd probably do it (9)

Discussion

Like many industrialised countries, New Zealand faces the challenge of an aging population. As expenditure in health care increases with age, understanding the issues and preferences that influence the health care decisions made by older individuals would seem to be an important aspect of providing good medical care. This is especially so when older individuals may be considering their choices and making decisions about the kind of medical treatment and care that is appropriate for them at the end of life.

Our participant group comprised individuals who are members of an organisation that supports legal medical practices that hasten dying at the end of life. We chose to focus on this group of individuals because they had made a conscious decision to become members of VESNZ and therefore had (presumably) given some thought to why they supported medical assistance to hasten death.

An important finding of this study indicates that some healthy, older individuals who support medical practices that hasten death have serious concerns about their (perceived) future incapacities and dependency on others, as well as their fears around becoming a burden. We also found that fear of future pain was not a dominant reason to support medical assistance to die. These findings also suggest that for some older people, their prior experience with health care and dying may be a strong factor in supporting medical practices that hasten death at the end of life.

The fear of becoming a burden on others is well documented within the end of life literature[30–33]although the majority of studies explore the concept of being a burden in persons with a terminal illness.[26–28, 34,35] Our study adds to the current body of research that fear of being a burden on others is not only felt by those who are terminally ill and facing their imminent mortality, but also by older individuals who are currently healthy and living independently in the community.

It is important to note that as individuals move through various stages throughout their lives their views on, and support of, many things may change. The person who fears disability or increasing dependence on others may reason that a future that includes these would be unacceptable to them.

Our research shows that for some individuals, support for medical assistance to hasten death may be in response to concerns such as these.

There is evidence from the Netherlands, and Oregon and Washington States (USA) that many individuals whose requests for an assisted death are approved by doctors, are not actively assisted to die at the end of life, or do not choose to use the lethal medication they have been prescribed[36-38]. For instance, in Washington in 2010[37], 87 individuals were prescribed lethal medication under the Death with Dignity Act.

Of the 67 individuals who died (for whom an After Death report was received by the Washington State Department of Health), 15 did not use the lethal medication to end their lives. While some of those individuals may have died of the underlying disease, some may have changed their mind about the manner of their death.

In their study examining the practices that surround euthanasia, Dutch and American researchers found that euthanasia discussions with patients, "in part serve a palliative effect, affirming social bonds and social identity at the end of life, and putting the onus on patients to continue discussions towards a euthanasia death"[38]. This open approach to discussions on dying and a willingness to engage with the patient may also contribute to a personal sense of control in the dying process.

Whilst it can be plausibly claimed that some of our participants may change their mind (about wanting a medically assisted death) as their future fears are not realised, or are successfully managed by other means, we cannot assume their current reasons for supporting medical assistance to hasten death will not have implications for their future medical treatment and care. This is an area of end of life decision-making that requires further research.

Whilst the findings of our study are not intended to be generalisable, they contribute to a wider body of knowledge around the influences and attitudes of personal preferences in regards to medical treatment and care at the end of life.

These findings highlight the need for health care practitioners to be aware of, and attentive to, the multifaceted reasons some healthy older individuals may have towards medical treatment and care at the end of life, especially where an individual expresses a desire to withdraw or withhold certain medical treatments.

Fear of losing one's independence and becoming dependent on others as one ages appears instrumental in influencing and shaping preferences made near the end of life. Although dependence on others is an essential feature of human development, and an essential condition of what it is to be a human person[29] some participants seemed to view dependency as deficiency; almost as though the loss of independence was a failure on their part.

Seale and Addington-Hall[39] found in their study which described the circumstances in which a representative sample of adults died, that certain forms of distress and dependency are more likely to lead to desires to die sooner, and to requests for euthanasia than others.

Prior experiences with health care that have involved the dying and death of a family member or friend may also deeply influence an individual's expectations of medical treatment and care available at the end of life and what they may want at the end of life. It was clear from several participants that the health practices they witnessed and often experienced (sometimes decades ago) would not be practiced today.

Informing older patients about advances in certain medical treatments and life expectancy outcomes may assist in alleviating concerns and fears around end of life issues. Inviting older patients to discuss such experiences may encourage dialogue around issues of dependency, the management of pain, and fears of becoming a burden on others.

As for study limitations it is important to note that all our participants identified as being of European descent. Thus we were unable to explore some of the particular issues of significance that may have arisen in the context of end of life decision-making for people who may have very different outlooks around dying and death.For instance, in communities where members have a more collectivist approach towards how decisions are made across the life span (as opposed to more individualistic approaches), support for medical hastening of death may be viewed very differently.

In an American study, Cahill and colleagues found that White older adults were more likely than Black older adults to discuss burden[40]. They concluded that the expression and meaning of burden differed according to ethnicity; "burden is expressed in different ways and meanings that sometimes correspond to the experiences of particular ethnic groups".

Exploring the reasons other groups of individuals have for supporting medical assistance in hastening death will add to a more nuanced picture of how end of life decision-making is approached and shaped. This should include individuals who live with chronic conditions, diverse ethnic groups, those who are disabled, younger individuals, and those who hold spiritual or religious beliefs that inform their decision-making.

We are currently undertaking a qualitative study that is exploring the reasons some healthy, older individuals oppose medical practices that hasten death. There is a scarcity of research exploring and understanding the issues arising for different groups of individuals near the end of life within the context of hastening death.

Furthermore the problem of dependency needs to be addressed at a deeper level than we were able to go in this study. Seale et al,[39] note that "*the issue of dependency in the elderly is a broad one, and may not be as amenable to remedy as certain symptoms have proved to be*".

Although surveys from many different countries indicate that increasing numbers of the public support medical assistance in hastening death, we still know very little about their reasons for doing so. We believe it is crucial to understand the reasons why people support medical practices that hasten death well in advance of such practices ever becoming legally available.

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