

Statement on hospice care and assisted dying

Introduction

The term 'assisted dying' is often used to describe circumstances in which a person is either helped to end their own life (physician-assisted suicide), or where there is a deliberate act to end a person's life (euthanasia).

Assisted dying is a complex subject that raises challenging ethical questions for hospice care. Hospice New Zealand recognises that across society there is a range of different views, and respects the right of everyone to take an individual position. It is our view that the question of whether there should be a change in the law is one for society to consider and for the parliament to decide.

The values of hospice and palliative care

The ethos of hospice and palliative care, as defined by the World Health Organisationⁱ, is that it 'intends neither to hasten nor postpone death'. This philosophy is a cornerstone of hospice care in New Zealand.

Our aim is to see the very best care for everyone facing the end of life. This means that:

- people who are dying can still live life well
- no one has to die in avoidable pain and suffering
- care is given to whoever needs it, whenever and wherever it is needed
- carers and the bereaved get the help and support they need
- people accept that dying is part of the experience of living.

We believe that access to good quality palliative care and support is a fundamental human right and globally this has been acknowledged at the 2nd Global Summit of National Hospice and Palliative Care Organisations 2005, Koreaⁱⁱ.

Hospice and palliative care must be provided according to the principles of equity, irrespective of age, race, gender, disability, sexual preference, ethnicity, faith, social status, national origin and the ability to pay for services. Palliative care must be available to all populations including vulnerable groups such as prisoners, sex workers and drug users and those with mental health issues.

Hospice and palliative care goes beyond managing the physical needs of people approaching the end of their lives. It places equal weight on their social, psychological, spiritual and emotional needs. It helps people to die with dignity.

As a result, good palliative care can greatly improve most people's experience of

living with and dying from a terminal condition. Many people using hospice services, whether it is the patient, family or friend find that they have a further positive phase of life which they never expected to have – perhaps coming to terms with their situation and experiencing a greater quality of life than they had imagined possible during their final weeks or months.

Hospice views on assisted dying

Hospice New Zealand does not support a change in the law to legalise assisted dying in any form. Nor do we consider that a change in the law would be in the best interests of the people cared for by hospice staff.

It is important to stress that hospices always works strictly within the law, which currently means it *is* a criminal action to help someone to commit suicide *and may result in prosecution.*

However, we recognise that the views of many staff and volunteers working within hospice care reflect the diversity of opinion in wider society.

Making decisions at the end of life

In recent years, there have been significant improvements in healthcare decision making, which give people greater control over decisions about their treatment and care.

It has also been identified that there is a lack of open discussion between health and social care staff and those approaching the end of life and those who care for them; this is one of the key barriers to the delivery of good end of life care. The New Zealand Palliative Care Strategy (2001)ⁱⁱⁱ sets an expectation of all palliative care providers; that they must provide information to the public around expectations of a palliative care service.

There is an emphasis in the palliative care sector on ensuring that services provided for people approaching the end of their lives are, as far as possible, responsive to their needs and preferences. This is evident through the introduction of advanced care plans where people are given the opportunity to consider what care they wish to receive, based on the best available information about what may lie ahead of them and what services are available.

Public and professional opinion on assisted dying

Polls of public opinion relating to assisted dying appear to consistently show widespread public support for a change in the law. In August 1995 a majority of MPs (61 to 29) voted against the introduction into Parliament of Michael Laws Death with Dignity Bill^{iv}.

A 1995 One Network News-Colmar Brunton poll issued found 62% of respondents were in favour of voluntary euthanasia, with 27% opposed and 10% undecided.

A Massey University Department of Marketing mail survey of 1000 New Zealanders, conducted in August and September 2002, found 73% supported assisted suicide for someone with a painful, incurable disease, provided it was a doctor who assisted. Support dropped to 49% for suicide assisted by someone else, such as a close relative vi.

The Death with Dignity Bill was introduced by New Zealand First MP Peter Brown into Parliament on 6 March 2003. The Bill's purpose was to:

Allow persons who are terminally and/or incurably ill the opportunity of requesting assistance from a medically qualified person to end their lives in a humane and dignified way and to provide for that to occur after medical confirmation, a psychiatric assessment, counselling, and personal reflection^{vii}.

Different opinions were expressed on euthanasia in Parliament. In July 2003 MPs voted 60 to 58 against the Death with Dignity Bill going to a Select Committee.

Professional

The attitudes of doctors and other clinicians appear to be at odds with public opinion.

Research published in 2009 in the UK found that 64% of doctors did not support the view that euthanasia or physician-assisted suicide should be allowed viii.

The New Zealand Medical Association (NZMA) is opposed to both the concept and practice of euthanasia and doctor assisted suicide^{ix}.

Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's request or at the request of close relatives, is unethical. Doctor-assisted suicide, like euthanasia, is unethical.

The NZMA however encourages the concept of death with dignity and comfort, and strongly supports the right of patients to decline treatment, or to request pain relief, and supports the right of access to appropriate palliative care.

In supporting patients' right to request pain relief, the NZMA accepts that the proper provision of such relief, even when it may hasten the death of the patient, is not unethical.

This NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical as stated in their 2005 Euthanasia and Doctor- Assisted Suicide policy^{ix}.

There remains some confusion both in the professions and in the public about the effect of opioids (strong painkillers), resulting in risks around these drugs not being prescribed to patients who need them.

Regulated use of pain relief is essential to relieve the physical suffering of those in severe pain at the end of life. Used correctly, strong pain killers such as opioids relieve pain without hastening death.

Medical undergraduate education in palliative care in New Zealand addresses some of the issues facing people near the end of life and work continues to expand the opportunities of health professionals from all disciplines to become competent and confident in all aspects of end-of-life care.

The Medical Council of New Zealand

The Medical Council of New Zealand (MCNZ) is a statutory body, but in 2003 a new Act came into force (the Health Practitioners Competence Assurance Act) which changed the role of the Medical Council quite significantly. The MCNZ are now required by the law to issue advice to doctors on moral issues (under s.118 of the Act one of the functions is now to "set standards of ... ethical conduct to be observed by [doctors]")^x.

Good medical practice (2008)^{xi} outlines the core standards doctors are expected to meet. The relevant sections on euthanasia are covered in paragraph 25 of Good medical practice, but some of the advice around "establishing and maintaining trust" (para 11), "giving information to patients about their condition" (13-15), "advising patients about your personal beliefs" (20) and "avoiding discrimination" (22-25) might also be relevant.

Informing the debate

There are many unanswered questions which require clarification before there could be any change in the law.

Hospice New Zealand believes that more research is needed to inform the public debate and future policy by government in particular:

- the extent to which palliative care can address the non physical aspects of suffering, through psychological, spiritual and social care, as well as physical care
- the quality and availability of palliative care in jurisdictions elsewhere in the world where physician-assisted suicide or euthanasia are permitted
- how patient views on assisted dying may change as people approach death and the impact of the psychological effects of approaching the end of life.

If there was to be a future change in the law, consideration would have to be given to:

- the full impact of a change in the law, considering evidence from other countries and jurisdictions which have made such a change, and the effects of different models of assisted dying xii
- how physician-assisted suicide or euthanasia would be implemented were it to be legalised. Many hospices take the view that this should not be a hospice role, because of the potential conflict with the values of hospice and palliative care, the impact on the perception of the hospice, and the possible

- implications for patient care. Research indicates that many health professionals would be reluctant to participate in assisted suicide or euthanasia
- the potential risk that vulnerable people might feel they should choose the option of assisted suicide, rather than being a 'burden' to their family or society or a drain on the healthcare system.

Recommendations

Hospice New Zealand believes that improving access to hospice and palliative care services should be the first priority of government.

Only when all New Zealanders have ready access to expert end-of-life care can a balanced debate begin. Most New Zealanders would prefer to die closer to their own homes, but in reality, many still end their life in acute hospitals, separated from their family and loved ones.

All patients should be made aware of options for hospice and palliative care, and should be offered an individual assessment of their needs to ensure that appropriate palliative care is being provided. This should be an integral part of advanced care planning.

We believe that palliative care should be routinely available to all who need it, and Government should ensure that public funding is made available to increase the availability of palliative care, whether provided by the hospital, at home (by the primary health care team), in residential aged care facilities or in hospices.

Greater education and training is needed to dispel the myths surrounding pain and symptom relief, and encourage all those prescribing medication for symptoms near the end of life to consult with hospice specialist clinicians and other palliative care experts where necessary.

About Hospice New Zealand

Hospice NZ exists to support member hospices in their work caring for people who are dying. We are the national organisation whose primary goal is to give voice to the interests, view and concerns of our member hospices.

Our purpose is to ensure all New Zealanders have access to the best possible hospice care at the end of their lives.

Currently all hospice services through the country are members of Hospice New Zealand. We have strong working relationships with the Palliative Care Council, Cancer Control Council and Ministry of Health as well as international links to similar organisations i.e. Help the Hospice (UK) Palliative Care Australia (AUS) Irish Hospice Foundation (IRE)

Hospice New Zealand would like to acknowledge and thank Help the Hospices (UK) for allowing us to adapt this information for use in a New Zealand context.

Help The Hospices Statement on Hospice Care and Assisted Dying (2009). Available at: www.helpthehospices.org.uk/EasySiteWeb/GatewayLink.aspx?alld=25420.

Appendix A: Understanding the terms

There is a great deal of confusion about the terms used to describe decision making at the end of a person's life. Terms are often used inter-changeably, when in fact they mean quite different things.

Euthanasia (voluntary)

The term euthanasia describes a situation in which a doctor intentionally kills a person by the administration of drugs, at that person's voluntary and competent request xiii. The term 'voluntary euthanasia' is sometimes used to describe instances in which a person has asked for this to happen. Euthanasia is illegal in New Zealand

Physician-assisted suicide

This is when a doctor intentionally helps a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request xiv. The doctor does not administer the drug. The person must be able to act to administer the drug themselves. Physician-assisted suicide is illegal in New Zealand

Palliative care

This is active care that hospices provide for people with advanced progressive illness, designed to help address pain and other physical symptoms, and to provide psychological, social and spiritual support. The ultimate goal is to support the best possible quality of life for the person with the illness and their family. Palliative care can be given over weeks, months or years.

End of life

Someone may be said to have reached this point when they are living with the condition they are likely to die from – in weeks, months or years – and are receiving care to cope with the symptoms of this condition.

Double effect

The principle of double effect means that treatment can be provided with the intention of alleviating symptoms which may have, as an additional unintended consequence, a shortening of life.

Non-treatment decision

A non-treatment decision is where doctors, in consultation with patients and families, believe that the withdrawal or withholding of a particular treatment is in the best interests of the patients for reasons of comfort, assessing distress versus benefit. For example, discontinuing chemotherapy, or deciding not to set up intravenous antibiotics for a patient.

The World Health Organisation defines palliative care as 'an approach that improves the quality of life of patients and their families facing the problem 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 or postpone death;
- integrates the psychological and spiritual aspects of patient 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 patients 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 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.
- ⁱⁱ 2nd Global Summit of National Hospice and Palliative Care Organisations 2005, Korea. Declaration document available from: http://www.hpc-association.net/
- Ministry of Health (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
- NZPD 549.(1995) Death with Dignity Bill. Wellington.
- ^V Bellamy, P (2003). *Voluntary Euthanasia and New Zealand*. Wellington; NZ Parlimentary Library.
- VI Massey University Press Release, 30.01.03. New Zealand Available from http://www.massey.ac.nz/~wwpubafs/2003/press_releases/30_01_03a.html
- vii Bills Digest No. 961, Death with Dignity Bill 2003 (2003). Wellington: NZ Parlimentary Library.
- viii Seale, C. (2009) "Legalisation of euthanasia or physician-assisted suicide: survey of doctor's attitudes" *Palliative Medicine*. 23, 3, 205-212
- New Zealand Medical Association (2005). *Euthanasia and Doctor Assisted Suicide*. Available at: http://www.nzma.org.nz/news/policies/euthanasia.html. Accessed 2009.
- Ministry of Health (2003) *Health Practitioners Competence Assurance Act.* Wellington: Ministry of Health.
- Xi Medical Council of New Zealand (2008). *Good Medical Practice: A Guide for Doctors*. Available at http://www.mcnz.org.nz/Publications/Goodmedicalpractice/tabid/293/Default.aspx Accessed 2009.
- For example, see the position paper from an EAPC Ethics Task Force, published in Palliative *Medicine* 17: 2, 2003.
- Materstvedt, L. J., Clark, D, Ellershaw, J, et al (2003) "Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force" *Palliative Medicine*. 17: 97-101.