

DRAFT FOR CONSULTATION

Access to End of Life Palliative Care Bill

Member's Bill

Explanatory note

General policy statement

Purpose

The overriding principle of this Bill is that all New Zealanders, wherever they live, will have the right to access the best possible care whenever they need it as they approach the end of their lives, so that they may die comfortably and with dignity.

Motivated by compassion, this Bill aims to ensure the geographically equitable provision of professional, high-standard specialist palliative care and appropriate support services, regardless of whether they are provided at home, in a hospital, in a hospice, or in an aged care residential facility.

The Bill amends two existing Acts to place obligations on the Minister of Health to ensure that the highest possible service standards for the provision of palliative care are in place at all times. It also places obligations on District Health Boards (DHBs) to develop and implement strategies to provide end of life care to all those who need it, including those in remote or isolated areas of the country.

This Bill was developed after consultation with palliative care experts, medical practitioners and service providers, patients, and loved ones of those who have died. It is also partly based on a member's bill currently before the British Parliament drafted by Baroness Finlay, a palliative care specialist and peer in the United Kingdom's House of Lords.

Background

Palliative medicine is a specific type of care for people whose illnesses are no longer curable. In a compassionate way, it enables them to achieve the best possible quality of life. It includes, but is not limited to, free access to appropriate pain management, psychological and emotional support for the person and their family, and information and support regarding the person's condition and end of life palliative care.

The concept of palliative care is holistic and encompasses the whole person—not just their physical symptoms but also their emotional, spiritual, cultural, and social needs. The care extends beyond the patient to include their loved ones and post-death and bereavement support for family, whānau, and friends.

In New Zealand, end of life palliative care is delivered in homes, hospitals, hospices, and residential care facilities, and is currently free of charge to patients. The cost of palliative care in a hospice environment is covered up to 70 percent from Government contributions with the remainder of funds raised from the community through the fundraising activities of New Zealand’s 35 hospices.

The ethos of hospice and palliative care as defined by the World Health Organization is that it “intends neither to hasten nor postpone death”, and the philosophy of Hospice NZ is that death is a natural part of life and, with greater investment in palliative care, end of life care can be improved for all.

There is a small number of New Zealanders who experience suffering and inadequate pain relief before their deaths. The reasons for this are complex and can relate to issues of geographical accessibility to appropriate palliative care and the competence of health practitioners who attend to patients at the end of life.

This Bill addresses these issues by obligating DHBs to put in place strategies to ensure that palliative care is accessible to all who require it, regardless of where they live, administered by fully trained professionals who can also provide expert advice to primary care providers such as general practitioners and nurses.

Around 80 percent of all people who die in New Zealand require end of life care, and there is a growing need to safeguard access to services: the number of people requiring palliative and hospice care is estimated to increase by 51 percent, from 24,680 in 2016 to 37,826 in 2038.¹ During that time, the age at death will increase as people live longer.

This Bill advances the goals contained in the New Zealand Health Strategy and the Healthy Ageing Strategy, supporting people in the final stages of life, whatever their age group, to make informed choices about their health and wellbeing through a person-centred, compassionate, and responsive system.

It also addresses the five priority areas identified in the Ministry of Health’s 2017 Review of Adult Palliative Care Services in New Zealand, which include increasing the emphasis on primary palliative care, improving quality in all settings, growing the capability of informal carers in communities, responding to the voices of people with palliative care needs, and ensuring strong strategic connections among providers.

Clause by clause analysis

Clause 1 is the Title clause.

¹ Review of Adult Palliative Care Services in New Zealand, Ministry of Health, 30 March 2017, <https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand>

Clause 2 provides for Part 1 of the Bill to come into force on the day after the date on which it receives the Royal assent and Part 2 to come into force 6 months later.

Clause 3 identifies the New Zealand Public Health and Disability Act 2000 (the **principal Act**) as the Act being amended.

Clause 4 amends section 42 of the principal Act to require DHBs to include information in their Annual Reports regarding their compliance with obligations to provide appropriate palliative care services to people who need them.

Clause 5 inserts a *new Part 4B* into the principal Act to place specific obligations on DHBs to provide appropriate palliative care services to people who need them, and to require DHBs to develop strategies for the provision of palliative care services.

Part 2 amends the Health and Disability Services (Safety) Act 2001 to insert a *new section 13A* requiring the Minister to ensure that service standards for the provision of palliative care are in force at all times.

Hon Maggie Barry

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Contents

		Page
1	Title	2
2	Commencement	2
Part 1		
Amendments to the New Zealand Public Health and Disability Act 2000		
3	Principal Act	2
4	Section 42 amended (Accountability documents under Crown Entities Act 2004)	2
5	New Part 4B inserted (Access to Palliative Care)	2
Part 4B		
Access to Palliative Care		
70H	Purpose of this Part	2
70I	Interpretation	2
70J	Palliative care support to be provided	3
70K	Duty to produce a strategy on provision of palliative care support	4
Part 2		
Amendments to the Health and Disability Services (Safety) Act 2001		
6	Principal Act	5
7	New section 13A inserted (Minister must ensure service standards for palliative care in force)	5
13A	Minister must ensure service standards for palliative care in force	5

The Parliament of New Zealand enacts as follows:

1 Title

This Act is the Access to End of Life Palliative Care Act **2018**.

2 Commencement

- (1) Part 1 of this Act comes into force on the day after the date on which this Act receives the Royal assent.
- (2) Part 2 of this Act comes into force on the day that is 6 months after the date on which it receives the Royal assent.

Part 1

Amendments to the New Zealand Public Health and Disability Act 2000

3 Principal Act

This Part amends the New Zealand Public Health and Disability Act 2000 (the **principal Act**).

4 Section 42 amended (Accountability documents under Crown Entities Act 2004)

- (1) In section 42(3)(i), after “section 23(1)(b) to (e)”, insert “; and”.
- (2) After section 42(3)(i), insert:
 - (j) a statement of how the DHB has given effect and intends to give effect to its obligations under **section 70J**, and its compliance with its strategy under **section 70K**.

5 New Part 4B inserted (Access to Palliative Care)

After section 70G insert:

Part 4B
Access to Palliative Care

70H Purpose of this Part

The purpose of this Part is to provide for geographically equitable access to specialist and generalist palliative care and appropriate support services across all DHBs.

70I Interpretation

In this Part, unless the context otherwise requires,—
family, in relation to a person, —

- (a) means members of the person’s family, whānau, or other culturally recognised family group, who—
 - (i) are in a close relationship with the person; or
 - (ii) have, in accordance with customs or traditions of the community of which the person is a part, responsibility for the person’s welfare and best interests; and
- (b) includes a person whose relationship to the person is established through 1 or more of the following relationships:
 - (i) spouse, civil union partner, or de facto partner of the person:
 - (ii) child, parent, guardian, grandparent, brother, or sister of the person:
 - (iii) stepchild, step-parent, stepbrother, or stepsister of the person

health and social care provider means a person or organisation that provides health or social care services

palliative care means care that is delivered to seek to improve the quality of life of persons with life-limiting illness or approaching the end of life, through the prevention and relief of suffering by means of early identification, assessment, treatment and management of pain and other problems whether physical, psychological, social or spiritual

specialist palliative care services means care services provided by multi-disciplinary teams of specialists in palliative medicine, palliative nursing and allied health professionals who have undergone specialist training in palliative care.

70J Palliative care support to be provided

- (1) A DHB, in exercising functions under section 23, must ensure that its resident population and other people as specified in its Crown funding agreement with palliative care needs have access to appropriate health services, including, but not limited to—
 - (a) access to pain and symptom management; and
 - (b) psychological support for the person and their family; and
 - (c) information and support regarding the person’s condition and palliative care.
- (2) For the purposes of **subsection (1)**, access must be provided to the following services:
 - (a) support to people with complex palliative care needs in their own homes, in hospitals, in hospices, in residential care facilities and elsewhere within the local community:
 - (b) direct admission of people with palliative care needs to hospice beds, including on an urgent basis when reasonably required:

- (c) support to other health and social care providers who are caring for people with palliative care needs:
- (d) specialist palliative care and hospice services which are available on every day of the week:
- (e) sufficient specialist professionals who are available to deliver services to meet all reasonable requirements:
- (f) sufficient equipment for any specialist professionals to enable the delivery of services to meet all reasonable requirements:
- (g) advice by telephone or video conference from a health practitioner who is qualified as a specialist in palliative care which is available at all times to professionals providing care to people with palliative care needs:
- (h) facilities to enable health practitioners to access essential medication at all times for palliative care patients being cared for in their own homes:
- (i) a point of contact that is available at all times for people with palliative care needs who are being cared for in their own home or usual place of residence, and those important to them, in the event that such persons are unable to access their usual sources of support:
- (j) appropriate systems to ensure that appropriate information about a person with palliative care needs can be made available with the consent of that person to relevant health and social care providers and to the ambulance services.

70K Duty to produce a strategy on provision of palliative care support

- (1) A DHB must prepare and publish a strategy for providing for palliative care needs as required by **section 70J**.
- (2) The strategy must include, at a minimum, the following—
 - (a) the expected palliative care needs of adults and children in their area:
 - (b) how the expected palliative care needs will be met:
 - (c) under what circumstances specialist palliative care services will be provided and how:
 - (d) the methods of data collection and reporting.
- (3) The strategy must—
 - (a) be published no later than 9 months after the commencement of this section; and
 - (b) be reviewed, revised as necessary, and republished at intervals of not more than 3 years.
- (4) For the purposes of this section, **publish** means that the strategy must be—
 - (a) notified in the *Gazette*; and
 - (b) published on an Internet site maintained by or on behalf of the DHB.

- (5) A notification in the *Gazette* for the purpose of **subsection (4)(a)** does not have to incorporate the strategy.

Part 2

Amendments to the Health and Disability Services (Safety) Act 2001

6 Principal Act

This Part amends the Health and Disability Services (Safety) Act 2001 (the **principal Act**).

7 New section 13A inserted (Minister must ensure service standards for palliative care in force)

After section 13, insert:

13A Minister must ensure service standards for palliative care in force

- (1) The Minister must ensure that service standards for the provision of palliative care are in force at all times.
- (2) For the purposes of this section, **palliative care** has the same meaning as in **section 70I** of the New Zealand Public Health and Disability Act 2000.