

DRAFT FOR CONSULTATION

Improving Access to 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 palliative 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 statutory, 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 service standards for the provision of palliative care are in place at all times. It also places obligations on Health New Zealand 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 an amendment to the Health and Social Care Bill for England by Baroness Finlay, a palliative care specialist and peer in the United Kingdom's House of Lords. This was accepted by the UK Government in February 2022.

Background

Palliative care 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, access to appropriate pain management, psychological, social, spiritual 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. Primary palliative care comes at a financial cost to patients, whilst specialist palliative care is usually free. The cost of palliative care provided by a community hospice is covered up to 65 percent (on average) from Government contributions with the remainder of funds raised from the community through the fundraising activities of New Zealand's 32 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 specialist palliative care, end of life care can be improved for all. Palliative care is explicitly recognised under the human right to health by the World Health Organisation.

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 accessibility to appropriate palliative care, lack of provision and the competence of health practitioners who attend to patients at the end of life.

This Bill addresses these issues by obligating Health New Zealand to put in place strategies to ensure that palliative care is accessible to all who require it, administered by fully trained specialists who can also provide expert advice to primary care providers such as general practitioners and nurses.

Around 90 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 specialist palliative care is estimated to increase by 61 percent, from 31,038 in 2021 to 49,977 in 2043. During that time, the age at death will increase as people live longer and consequently, the proportion of deaths where palliative care would be of benefit will increase to nearly 94%.

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.

Clause 2 is the commencement clause and provides for Part 1 of the Bill to come into force on the day after Royal assent and Part 2 to come into force 6 months later.

Part 1

Amendments to the Pae Ora (Healthy Futures) Act 2022

Clause 3 identifies the Pae Ora (Healthy Futures) Act 2022 as the Act being amended.

Clause 4 inserts *new section 46A* to require the preparation of a Palliative Care Strategy.

Clause 5 amends section 55 to require Health New Zealand to include information in their annual report on locality plans regarding their compliance with obligations to provide palliative care services.

Clause 6 inserts *new subpart 6A* into Part 2 of the Act to place specific obligations on Health New Zealand to provide palliative care services.

Part 2

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

Clause 7 identifies the Health and Disability Services (Safety) Act 2001 as the Act being amended by Part 2 of the Bill.

Clause 8 inserts *new section 13A* to require the Minister to ensure that service standards for the provision of palliative care are in force at all times.

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The Parliament of New Zealand enacts as follows:**1 Title**

This Act is the Improving Access to Palliative Care Act **2024**.

2 Commencement

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

Part 1**Preliminary provisions****3 Principal Act**

This Part amends the Pae Ora (Healthy Futures) Act 2022.

4 New section 46A inserted (Palliative Care Strategy)

After section 46, insert:

46A Palliative Care Strategy

- (1) The Minister must prepare and determine a Palliative Care Strategy.
- (2) The purpose of the Palliative Care Strategy is to provide a framework to guide health entities in providing equitable access to specialist and primary palliative care and appropriate support services across all localities.
- (3) The Palliative Care Strategy must—
 - (a) contain an assessment of the expected palliative care needs of adults and children in each locality;
 - (b) explain how the expected palliative care needs will be met in each locality;
 - (c) describe how specialist palliative care services will be provided equitably;
 - (d) set out methods of data collection and reporting;
 - (e) set out requirements for palliative care training of primary health and social care providers.
- (4) **Subsection (3)** does not limit what may be included in the Palliative Care Strategy.

5 Section 55 amended (Locality plans)

After section 55(5), insert:

- (5A) The report must contain a statement describing—
 - (a) compliance by health entities with the strategy under **section 46A**; and

- (b) how **section 60C** will be given effect for the duration of the plan; and
- (c) how **section 60C** was given effect during the previous locality plan.

6 New subpart 6 of Part 2 inserted

After section 60, insert:

Subpart 6A—Improving Access to Palliative Care

60A Purpose of this subpart

The purpose of this subpart is to provide for equitable access to specialist and primary palliative care and appropriate support services across all localities.

60B 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

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

primary palliative care services means care services provided by individuals and organisations who deliver palliative care as a component of their service but are not specialist palliative care services

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

60C Palliative care support to be provided

- (1) Health New Zealand must ensure that each person with palliative care needs, regardless of their age or where they live, has access to appropriate health services, including, but not limited to—
 - (a) access to pain and symptom management; and
 - (b) psychological, social, cultural, and spiritual support for the person and their family; and
 - (c) information and support regarding the person's condition and palliative care; and
 - (d) bereavement care.
- (2) For the purposes of **subsection (1)**, access must be provided to the following services:
 - (a) specialist palliative care services for persons with complex palliative care needs in their homes, in hospitals, in hospices, in residential care facilities, and elsewhere within the local community:
 - (b) direct admission of people with complex palliative care needs to hospice and specialist palliative care beds, including on an urgent basis when reasonably required:
 - (c) specialist support and education to primary palliative care service providers who provide care for people with palliative care needs:
 - (d) specialist palliative care and hospice services that 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 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) essential medication at all times for palliative care patients wherever they are:
 - (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 providers and to the ambulance services:
 - (k) timely access to psychological, social, cultural and spiritual support for the person and their family, including bereavement support.

Part 2

Amendment to Health and Disability Services (Safety) Act 2001

7 Principal Act

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

8 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 60B** of the Pae Ora (Healthy Futures) Act 2022.