



**To: Justice Select Committee**

**Regarding: End of Life Choice Bill**

**From: Hospice New Zealand**

**Dated: 21 February 2018**

As an organisation Hospice New Zealand strongly opposes and disagrees with the intent of the End of Life Choice Bill.

**Background:**

Hospice New Zealand is the national organisation representing all hospice services throughout the country. Our work supports hospices, healthcare providers and the public through the provision of research, education, workforce development, awareness and quality standards.

Currently there are 35 hospice services in New Zealand, each provide a range of services based on the needs of the community. In all areas, hospice services work in collaboration with primary care and aged residential care to provide support.

Each service is based on the bedrock values of choice, respect, dignity, empowerment and compassion.

Our vision is for everyone with a life limiting condition and their families and whanau to have access to the best possible palliative care. Access to palliative care will ensure they are well supported and cared for and their individual needs are listened too and addressed.

**What is hospice?**

Many people think of hospice as just a building, when in fact it is a philosophy of care. Although most hospices in New Zealand have inpatient facilities, the majority of people are cared for in their homes.

Anyone living with a life limiting condition – e.g. heart failure, chronic respiratory disease, motor neurone disease, multiple sclerosis or cancer – can access and benefit from hospice services.

Our aim is to help people make the most of their lives; to live every moment in whatever way is important to them. Depending on when our services are sought, living every moment can take on a different meaning. It might be going to watch a sporting or cultural event; it might be time with family and friends, through to holding someone's hand or feeling the sun on their skin through a window.

The most important aspect is that we celebrate that that person is alive and ensure they are receiving the care and support both they and their family need - both before and after a death.

Hospice care has a unique whole person approach – which means physical, spiritual, emotional and social needs are acknowledged as being equally important – a multidisciplinary team provides care for each person who is dying and their families and friends, both before and after a death.

In New Zealand hospice services are independent charitable organisations providing care and support free of charge to the user.

Whilst free to people using hospice services it costs a lot to provide. Each year our services cost over \$100M nationally.

As an essential health service provider, on average hospice services receive around 60% of funding from Government; but financial support from the community is essential to meet the shortfall – each year hospices must raise over \$45M nationally.

We wish to make the following comments on the intent of the End of Life Choice Bill:

**1. Euthanasia/physician assisted suicide is against the core values of palliative care.**

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

We believe death is a natural part of life and with greater investment in palliative care, end of life care can be improved for all New Zealanders.

**Clause 8**

*(c) ensure the person fully understands his or her other options for end of life care.*

Although we generally agree with the underlying intent of this clause, people understanding their care options, to put the option of physician assisted suicide alongside palliative care undermines the intent of palliative care and may place pressure on people with a terminal illness (or their proxy) to choose immediate death rather than living until they die naturally.

**2. With the right palliative care a person can have a good quality of life with their dignity maintained and their symptoms managed.**

**Clause 4**

*(e) experiences unbearable suffering that cannot be relieved in a manner that he or she considers tolerable*

The experience of suffering and tolerance of treatment is entirely subjective. What some people find unbearable others live with on a daily basis e.g. someone who receives support in showering or toileting, people who are unable to walk unaided, people who are not able to communicate verbally. Many people live with significant chronic pain and conditions for many years. Suffering varies from day to day and sometimes hour to hour.

As this feeling is personal it cannot be challenged or called unreasonable and therefore cannot be determined by testing.

It is often perceived that someone with a terminal diagnosis has no prospect for improvement – which might be the case in terms of changing the course of their illness, however, with the right support, they still have hope for the future and can continue to enjoy some things in life that have always brought them joy.

## Clause 8

(e) *Encourage the person to talk about his or her wish with others such as family, friends and counsellors and*

(f) *ensure that he or she is not obliged to talk to anyone*

We disagree with this clause as it is entirely possible a person's family or whanau may be unaware of a request for physician assisted suicide by their loved one.

Family members frequently play an integral role in the care of someone with a terminal illness, without knowledge of a request for assisted suicide, they may be unable to seek additional or alternative support to address what has motivated their loved one to make a request, therefore leaving them out of crucial health care decisions.

### **3. Legalising physician assisted suicide will place pressure on vulnerable people – those living with terminal illness, disability, mental health issues – for fear of being a financial, emotional or care burden.**

Those who advocate for a change in legislation come from the premise of an individual's right to choose, we don't disagree with that concept, in fact hospice care is based on providing choices and empowerment through individualised care.

## Clause 4

(c) *suffers from a terminal illness likely to end his or her life within 6 months*

We disagree with this clause and criteria. When does the choice to die become the duty to die?

A person with a terminal illness is in a vulnerable position. They may be fearful of how their symptoms will progress and what their death will be like. They may also fear leaving family, whanau and friends behind and the effect their illness will have on others. They may feel a burden on their family, carers and society and they can feel pressure to request physician assisted suicide.

Being dependant on others happens at all stages of life – babies and children for example, look to their caregivers for a huge amount of support, we should show the older members of our community the same respect, supporting them as they age, rather than creating a sense of burden around their ongoing care/needs.

In Oregon the most common reasons for assisting suicide are social/existential rather than medical – 49% fear being a burden to family and/or friends/caregivers. Oregon Health Authority, Public Health Division, Death with Dignity Act, Data Summary 2016

<http://public.health.oregon.gov/ProviderPartnerResources/Evaluationresearch/>

The determination of prognosis is difficult and unreliable. According to the Journal of Medicine and BMJ Quality and Safety, published studies indicate misdiagnosis occurs anywhere from 10-15% of the time. (Gerber ML. *The incidence of diagnostic error in medicine. BMJ Qual Saf* 2013.)

(c) ii *a grievous and irremediable medical condition*

We disagree with the intent of this clause as it increases the scope for physician assisted suicide to people who do not have a terminal diagnosis and may be living with conditions that have no cure.

These conditions for eligibility are very similar to those that apply in the Netherlands, which now provides euthanasia to people with disabilities, with psychiatric disorders and with dementia. Cases

there have included a person with “aging-related conditions, including arthrosis of the knee, pain from vertebral compression fractures caused by osteoporosis, headaches, poor kidney function, incontinence, impaired vision, atrial fibrillation and hemiparesis following a CVA” and “the feeling that life was no longer meaningful” because of functional decline and dependence on others (<https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports> Annual Report 2014, p. 23)

#### **Clause 8**

(h) *do his or her best to ensure that the person expresses his or her wish free from pressure from any other person by:*

*(ii) talking with members of the persons family approved by the person*

We strongly disagree with this clause as it appears to be contradictory – a physician must do his or her best to determine a request has been made free from pressure but are limited in their ability to talk to family members. If the person making the request is subject to family pressure they are unlikely to give approval to the physician to speak with these people. It is difficult to detect coercion from behind a closed door. Therefore, a true picture of the situation motivating the request may not be clear.

New Zealand has a high incidence of elder abuse, Age Concern reports it receives more than 2000 cases of elder abuse and neglect each year, over 75% of cases involve psychological abuse. [https://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ\\_Public/Elder\\_Abuse\\_and\\_Neglect.aspx](https://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ_Public/Elder_Abuse_and_Neglect.aspx)

#### **4. Good palliative care is founded on a trusting relationship between patient, family and health care professional this is undermined by euthanasia/physician assisted suicide.**

As an organisation we disagree that physician assisted suicide should be available in New Zealand as it undermines the doctor patient relationship and we suggest the proposed practice of assisted suicide has no place in the medical profession as it is unethical.

#### **Clause 7**

(2) The attending medical practitioner must tell the person that –

(a) the medical practitioner has a conscientious objection: and

(b) the person may ask the SCENZ group for the name and contact details of a replacement medical practitioner.

We object to this clause and disagree that it allows medical practitioners the ability to conscientiously object. By instructing the medical practitioner to tell the person they may seek details for another practitioner, they are being forced to facilitate physician assisted suicide by referral. We would suggest this is a breach of human rights for clinical staff, when viewing human rights from the impact on a population perspective, rather than an individual one. The human right of choice is breached by this clause for a range of healthcare professionals working in hospice and other settings.

A referral to a member of the SCENZ group would transfer the ongoing care of the person, undermining any long-term relationship held by the existing physician and patient.

This clause does not allow care providers such as hospice services to have an overarching policy or practice of not providing physician assisted suicide. As euthanasia and physician assisted suicide are against the ethos of palliative care, we believe this will have a detrimental impact on the workforce.

As an organisation we are concerned about the psychological impact on existing staff managing requests for physician assisted suicide and the requirement to refer a patient onto a SCENZ member.

There is also potential impact on all hospice staff, volunteers and other patients and family members if someone under hospice care has a request confirmed and the assisted suicide is carried out. Could physician assisted suicide take place in a hospice inpatient unit – provided by a SCENZ member if as an organisation we are unable to conscientiously object? The same could be suggested for hospital and aged residential care facilities.

The availability/legalisation of physician assisted suicide could seriously impact our ability to recruit and retain staff and volunteers as well as impact on our support from the community.

The [New Zealand Medical Association Position Statement](#) on Euthanasia reiterates the opinion that euthanasia and physician assisted suicide are unethical. “The 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.”

The [Australian & New Zealand Society of Palliative Medicine \(ANZSPM\) Position Statement](#) on Euthanasia (2017) states: “In accordance with best practice guidelines internationally, the discipline of palliative medicine does not include the practices of euthanasia or physician assisted suicide.”

In conclusion Hospice NZ does not support any change in the law to legalise euthanasia or assisted suicide in any form. We appreciate there are a range of views on this challenging and emotive topic and respect everyone has a right to their own opinion. We believe the priority should be on improving access to hospice and palliative care services to ensure everyone receives quality care regardless of diagnosis, age, gender, ethnicity, socio-economic status or location.