



Submission to the Health Select Committee regarding the investigation into ending one's life in New Zealand.

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1. Background information

The Hospice Story

Hospice is a global movement that has radically changed the way we approach death and dying. The Hospice movement condemns the neglect of people who are dying and calls for high-quality pain and symptom management for all who need it. Hospice approaches death as a natural phenomenon rather than a clinical failure, and world-wide more than 58 per cent of countries have an active hospice palliative care service.

Here in New Zealand the three founding hospices were established in the late 1970's – Te Omanga Hospice in Lower Hutt, Mary Potter Hospice in Wellington and Mercy Hospice Auckland.

The driving force behind the establishment of all hospice services in New Zealand has been the desire to transform the experience of dying. Hospice care is one of New Zealand's outstanding success stories.

Snapshot of hospice services:

Some key figures for hospice services looking at a 12 month period:

16,000 – more than 16,000 people with a life limiting condition receive support from the 35 hospice services throughout the country. Support was also given to people's families and friends both before and after a death.

142,000– Hospice is a philosophy of care and whilst most hospice services have inpatient facilities the majority of people are cared for in their own home. Each year hospice staff make more than 142,000 visits to people in the community.

11,300– Hospice services are firmly grounded in the community and rely heavily on people giving their time to support our work. Each year more than 11,300 people donated their time volunteering to work for hospice.

1,100,000– The generous team of volunteers give in excess of 1 million hours of their time to support hospice services each year. Volunteers do a variety of work in a huge range of roles – we are extremely grateful to anyone who gives their time freely to hospice.

Who is Hospice New Zealand?

Hospice New Zealand was established in 1986 to represent all hospice services in New Zealand. It supports hospices, stakeholders and the public through the provision of research, education, workforce development, and healthcare standards.

Today we have over 35 hospice services of all sizes, each one developing in their community in response to the local need. In some centres the hospice team provides a full range of services, whilst in other areas the hospice collaborates with community services and private hospitals to provide support.

Each and every hospice is built on the bedrock values of respect, choice, empowerment, holistic care 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. We take pride in helping New Zealanders with a life-limiting condition to “live every moment” and have a range of services available to assist with this.

Our purpose, in order that everyone has access to quality palliative care, is to provide national leadership and advocacy for all members and influence and work with the wider palliative care sector.

Strategically our focus is national and is reflected in our high level goals:

1. Community Awareness

To engage with the community to build:

- our understanding of their needs, and
- their awareness and understanding of the hospice philosophy and services.

2. Leadership

To provide national leadership, strategic direction, and support through collaboration with members and the wider sector, in order to integrate hospice philosophy into all palliative care.

3. Advocacy

To work with government to strategically influence policy, funding and equity of access, on behalf of members and the wider sector.

4. Workforce Capability

To ensure the continued availability of a high-capability workforce including everyone delivering palliative care, by:

- defining current and future needs
- coordinating the development and delivery of national education resources and programmes
- promoting the best use of scarce resources – medical specialists and nurse practitioners.

5. Quality Outcomes

To extend the quality and standard of palliative care for patients, family and whānau to all settings, and facilitate the development of measures to demonstrate the value of palliative care.

6. Fundraising for sustainability

To build the brand of hospice to ensure benefits from national fundraising opportunities are realised for Hospice NZ & members to augment government funding.

What is hospice?

Many people think of hospice services 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, motor neurone disease, MS 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 equally important – a multidisciplinary team provides care for 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.

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, hospice services receive the majority of funding from Government; but financial support from the community is essential to meet the shortfall – each year hospices must raise over \$45M nationally.

2. The effectiveness of hospice services when it comes to providing support to people with a life limiting condition (terminal illness) who have a desire to end their lives.

Hospice services and palliative care, as defined by the World Health Organisation “intends neither to hasten nor postpone death.” This philosophy is the cornerstone of hospice care throughout the world.

We believe death is a natural part of life and with the right palliative care a person can have a good quality of life, with their dignity maintained and symptoms managed to help them feel as comfortable as possible. It is essential that services are also in place to support family and whanau both before and after the death of their loved one.

A person with a life limiting condition (terminal illness) is in a vulnerable position. They may be fearful of what death will be like and the symptoms they may experience as their illness progresses. This is a time where the art and science of palliative care come together. The art is listening to that vulnerability and discussing ways this can be managed. This could take the form of end of life planning, funeral arrangements or making sure loved ones are taken care of.

The holistic nature of hospice services – providing support for a person’s social, emotional and spiritual wellbeing, as well as their physical symptoms – by a skilled multidisciplinary team, works on an individual basis to address what is contributing to a person’s suffering. There is no specific formula for what a person will receive or expect from a hospice – it is based on what they need. At a time and place that is right for them, their family and whanau.

What one person may consider unbearable suffering another person is able to live with on a daily basis. The impact of no prospect for improvement (a terminal diagnosis) is subjective. It is often perceived that people with a terminal diagnosis have no hope – however they can and do continue to enjoy the things in life that have always brought them joy. With good support people who are at the end of their lives can develop a greater depth of meaning to life, enjoying time with the people and things that are important to them.

An underlying factor that drives a desire to end life is often fear. Fears include leaving family, whanau and friends behind and the effect their illness is having on others. People may feel that they are a burden on their family, carers and society and can then feel pressure to end their lives. The angst that comes with dying is not confined to the physical.

Again, listening to and exploring these fears can help to address them and put strategies in place to move beyond and complete unfinished business and prepare mentally and spiritually for death.

It is easy to say “yes” to euthanasia before we are faced with terminal illness, especially when public perception is heavily shaped by the stories told by media. Headlines of bad news stories, people in distressing situations without support or options sell papers far more readily than stories of good deaths and experiences. This gives a very one sided view of end of life issues to the general public which feeds into individuals fears of death and dying.

The reality is that life is incredibly precious to people who are dying, every moment matters and very rarely do people involved in hospice services/receiving palliative care make a request for euthanasia. If and when they do – they are listened to and given the opportunity to discuss what is driving that request. There is an opportunity that comes with this conversation – to identify need and put support in place to address the concerns which sit under the desire for life to end.

As an organisation we are concerned about the risks around legalising euthanasia. It may create a barrier for people who need to access hospice services as they may perceive that their wishes will not be listened to by hospice staff or feel a pressure to end their lives should that option be available. This is particularly important for the most vulnerable in our community – older people, those living with disabilities and people with mental health issues.

We must remember that dying is a natural part of the life process for human beings and focus on helping people live well until they die.

3. Ensuring the future needs of people who are at the ends of their lives are met by hospice services.

Collaboration

We are aware that with our aging population, collaboration with our colleagues in aged residential care and primary care will be essential to ensure the needs of dying people can be met.

Currently we recognise that a third of all people who are dying in New Zealand are dying in aged residential care facilities. Aged care staff are dealing with a huge number of people with a palliative care need. To support staff that are caring for residents approaching the end of their lives Hospice NZ in partnership with the Ministry of Health has developed the Fundamentals of Palliative Care. This is a ten package learning series delivered by hospice services to their community-based colleagues. Since the launch in 2012 there have been over 25,000 packages delivered in more than 450 aged care facilities throughout the country.

Hospice services take an active role in supporting colleagues in primary care. Primary care providers are able to access advice from hospice doctors, nurses and multidisciplinary team members on a regular and ongoing basis. This means patients receive quality palliative care without an official referral to hospice, so hospice care reaches far wider than the people officially on hospice records.

Encouraging people to discuss death and dying – awareness and acceptance of hospice support

Death and dying are still topics that people feel uncomfortable discussing with their family, friends and as a community.

In a 2015 research study of 1000 New Zealanders fewer than half of all those surveyed had shared what will be important to them as they approach the end of their lives. The majority indicated this is not something they want to talk or think about and some find such a topic to be too emotional to share.

Just over half of all those surveyed have completed a Will, those more likely to have done so tend to be older, in a relationship (past or present), and had more personal experience with palliative care and death.

Open conversations at a community level will reduce the taboo of death – therefore decreasing fear and anxiety about something that will happen to us all at some point. Our lack of openness has affected the quality and range of support and care services available to patients and families and acceptance of referral to hospice services.

People can be referred to hospice services at the time of diagnosis. Early referral has been shown to extend people's quality of life and also ensures a suitable long-term support network is created for the person's carer, family and whanau.

Talking about death and dying does not bring it closer, what it does do is help families understand each other's wishes, enabling them to honour them when the time comes.

Workforce capability

There are workforce shortages in many areas of health care and this is true for the hospice and palliative care sector. The identified areas of shortage are around medical specialists and in the future will also include suitably experienced and qualified nurses.

To ensure the workforce is prepared for the predicted increase in demand for end of life care we need to ensure a career in healthcare in New Zealand remains an attractive option. Alongside that we are committed to establishing a long-term career palliative care pathway for medical, nursing and allied health professionals.

Funding & volunteer support

Funding will always be an important consideration. Hospice services are provided free of charge which means there are no financial barriers to accessing support. As an essential health service hospices receive the majority of funding from Central Government via contracts with DHB's. The remainder of funds come from the community via donations.

It is important that the community remains engaged and supportive of hospice via financial opportunities to support and also volunteering opportunities. All hospice services in New Zealand were founded and grew out of the community – maintaining the link has benefits for awareness, support and access from people requiring hospice care.

4. Recommendation

Hospice services and palliative care as defined by the World Health Organisation “intends neither to hasten nor postpone death”. This is the cornerstone of hospice care in New Zealand – euthanasia and physician assisted death goes against this because it hastens death.

Quality palliative care is based on a trusting relationship between patient, family and the health care provider, this is undermined by euthanasia. Euthanasia or physician assisted death says it is okay to kill people under certain circumstances.

As an organisation we believe that death is a natural part of life and with the right palliative care a person with a life limiting condition can have good quality of life. The palliative care team will work with the person to manage their symptoms and help them feel as comfortable as possible with their dignity maintained. Services are also in place to support family and whanau both before and after the death of their loved one.

Additionally, should euthanasia or physician assisted death become legal, we predict that there will be a large increase in the need for extra bereavement and grief services for families and whanau as literature highlights the strong grief and feelings of guilt evident in countries where this act is legal.

The holistic nature of hospice services – providing support for a person’s social, emotional and spiritual wellbeing as well as their physical symptoms – can help people to develop a greater depth of meaning to life and therefore, enjoy the time they have with the people and things that are important to them.

Hospices throughout New Zealand highlight the importance of allowing a natural death as experienced staff recount how this important time allows for benefits such as opportunities for reconciliation of any lasting family tensions – shortening a patient’s life prevents this important healing process.

As an organisation the hospice sector does not support any change to the legislation around euthanasia or physician assisted death – in our experience good palliative care allows people to die as comfortably as possible. We must focus on helping people to live well until they die.