

I, Mary Gemma Schumacher, of Wellington, Chief Executive Officer, swear:

1. I am the Chief Executive of Hospice NZ. I have held that role for the past 10 years. Prior to this national leadership role, I was Chief Executive of Mary Potter Hospice in Wellington for ten years. I have a Masters in Social Work and have previously managed community, rest home and private hospital services for older people. I also volunteer as a Board Member for the Home of Compassion in Wellington.
2. Hospice NZ was founded in 1986. Hospice NZ is the national organisation representing all hospice services. We give voice to the views and concerns of our membership. Our vision is every New Zealander has access to good palliative care at the end of their lives. The main areas of Hospice New Zealand's work are advocacy, awareness raising, education, standards, data and information and research.

The hospice movement

3. Hospice is a movement that has condemned the neglect of people who are dying in our society, called for high quality pain and symptom management for all who need it and has sought to reconstruct death as a natural phenomenon rather than a clinical failure.
4. Dame Cecily Saunders is credited as the founder of the modern hospice movement, the world's first dedicated hospice facility was opened in 1967 in London under her guidance. The hospice was founded on the principles of combining teaching and clinical research, expert pain and symptom relief with holistic care to meet the physical, social, psychological and spiritual needs of its patients and those of their family and friends.

Hospice palliative care services in New Zealand

5. Hospice services in New Zealand began in the late 1970's with the three founding hospices – Mary Potter Hospice in Wellington, Te Omanga Hospice in Lower Hutt and Mercy Hospice in Auckland. These were established and largely funded by their local communities.
6. 30 years later there are now 29 hospice services providing care and support for people with any life limiting illness from Kaitaia in the North to Invercargill in

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the South. Hospice services are provided free of charge to anyone with any life limiting condition. There are no barriers to accessing care based on socio-economic status, religious beliefs, age, ethnicity or diagnosis. Referrals can be made by GPs, district nurses, hospital staff or by self-referral.

7. Whilst most hospice services have an inpatient facility, the majority of people using hospice are cared for at home in the community. In 2014 hospice staff made more than 142,000 visits to people in their place of residence. People can access inpatient services for many different reasons during their end of life care – for respite for their carer, specialist symptom control and management or for their final days before they die if that is what they have chosen.
8. Hospice palliative care services are part of the health system and receive the majority of their funding from contracts with Government via the District Health Board network. Community support via fundraising is vital to make up the shortfall in this funding as is the support of people giving their time as volunteers.
9. Each year hospice services must raise over \$45M from the community to keep services free of charge. More than 11,000 people give over 1 million hours volunteering to support hospice each year.
10. The 29 hospices services cover the majority of the country. In areas such as the West Coast of the South Island the hospice service located in the closest urban city (Christchurch) supports district nurses and GPs to provide palliative care services to the community. Hospice New Zealand is working with Government, primary health care providers and residential aged care providers striving to increase accessibility to good palliative care regardless of setting.
11. Earlier this year the Government showed the continued commitment to making hospice care available to all New Zealanders by confirming an increased funding contribution of \$20M per annum for hospice services.
12. Hospice recognises that a third of people who are dying in New Zealand are dying in aged residential care facilities. Aged care staff are dealing with a large number of people with a palliative care need. To support staff who are caring for residents who are approaching the end of their lives, Hospice NZ in partnership with the Ministry of Health has developed the Fundamentals of



Palliative Care. A nine package learning series that is delivered by hospice services to aged residential care facilities in their communities. Since the launch in 2012 there has been more than 25,000 packages given to over 450 aged care facilities.

13. Hospice services take an active role supporting our colleagues in primary care through a range of education and training opportunities that are open to all primary care providers. Nationally a monthly lecture series attracts an average of 345 people each month. The syringe-driver training programme trained over 1500 health care professionals in 2014. A syringe driver is a portable battery operated device that administers medications subcutaneously over a chosen period of time. A syringe containing the medication is attached to a driver which pushes the plunger forward at an accurately controlled rate. Hospice services run training sessions for their local healthcare community on an on-going basis.
14. Primary care providers are able to access specialist advice from hospice doctors, nurses and multidisciplinary team members on a regular and ongoing basis.

Hospice philosophy of care

15. Hospice is a philosophy of care, not just a building. Anyone with a life limiting condition – e.g. cancer, multiple sclerosis, motor neurone disease, heart failure, dementia and many chronic conditions – can access palliative care from hospice services.
16. Hospice care has a unique whole person approach – which means physical, spiritual, emotional and social needs are treated as being equally important. A multi-disciplinary team of health care professionals are involved in each person's care – a doctor, nurse, social worker, spiritual care advisor, counsellor, kaitiaki/cultural liaison, occupational therapist/physiotherapist can be involved in developing each individual's care plan. Care is provided for the person with the life limiting condition and also their family and whanau both before and after a death.

17. Ongoing assessment of symptoms expressed by the person, their family and whanau and careful monitoring and therapeutic use of medications being used for symptom relief are paramount for quality palliative care.
18. Hospice palliative care is continually developing driven by development studies and new research. In recent years hospice services have become much better positioned to assess symptom distress and alleviate suffering. It is not always an easy process but comfort is provided by a committed presence, compassion and specialist knowledge.
19. We acknowledge the existential nature of distress that accompanies the experience of dying people. There are aspects of distress that defy the most advanced medicines and treatments but remaining present with the person and listening unconditionally can reduce that distress and allow the person to feel hopeful and find meaning in life.
20. As people face the end of their lives they need to feel loved and valued and receive care that makes their suffering and sadness bearable. It is during these days that people are able to reflect on their life, complete unfinished business and prepare mentally and spiritually.
21. 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 develop a greater depth of meaning to life. Over and over again we see that people and their families who are well supported appreciate and value spending what time they have left have with the people and things that are important to them.

The importance of communication

22. Hospice services provide patient centred care, all decisions are patient led and hospice staff journey alongside. A key element of the journey is always being present, continually listening and supporting patients and their family and whanau without judgement. The aim is to provide a safe space for all involved to fully discuss and explore current feelings and options.
23. From experience we know that people who are coming to the end of their lives are vulnerable, there is vulnerability in all life, but when people are closer to the

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end of their lives the feeling of vulnerability can be heightened. People using hospice services could be described as being at their most real/raw, there is nothing to hide. This is when the art and the science of providing palliative care comes together. The art is listening to that vulnerability and discussing what ways this can be managed. This may take the form of end of life planning, funeral arrangements, planning for death or taking care of loved ones.


Euthanasia and assisted suicide have no place in palliative care

24. 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 in New Zealand. Euthanasia and physician assisted death go against this because both hasten death.
25. Hospice services acknowledge death as 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.
26. People can be referred to hospice services at the time of diagnosis. Early referral has been shown to extend peoples quality of life and assist with their planning ahead and thinking about the care that is important to them, fully understanding what services and care are available. Early referral also ensures a suitable and long term support network is created for the person's carer, family and whanau. In some circumstances there may be barriers to referral that come from a lack of knowledge, personal opinion/experience of the primary health care provider. In the majority of cases a person can be jointly supported by the hospice physicians and their GP.
27. Legalising physician-assisted death may create a barrier for people who need to access hospice services. They may become fearful that their wishes will not be listened to by hospice staff and also 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. They may feel a burden on their family, carers and society. They may worry about the affect their illness is having on others – this may lead to pressure to request euthanasia or physician assisted suicide, even when it is not what the person would want for themselves if they believed they


be could truly cared for through to their natural death. It is the core function of the hospice services to provide that assurance and that care. Euthanasia and assisted suicide are in direct contradiction to that objective.

SWORN

at Wellington this 11th day of
May 2015
before me:

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Mary Gemma Schumacher


Joyce Velasco

A (Deputy) Registrar of the High Court of New Zealand