



## PUBLIC AWARENESS

As an organisation, Hospice NZ continually assesses the extent to which we are meeting the diverse needs of our communities. Each year, we identify not only the achievements we can celebrate, but also areas for development and improvement. Raising awareness of Hospice services is vitally important to ensure we meet the needs of people who may further benefit from the care and support of their local hospice – those with non-cancer diagnoses, for example, or those with advanced dementia and frailty. This Hospice Awareness Week, please help us spread the word about Hospice care with your friends and family, colleagues and communities.

At our recent AGM, we bid farewell to Lisa Roberts, Chair of the Hospice NZ Board, and also Bidy Harford, who served on our Board since 2006 and as Chair for several years. Our sincere thanks to both Lisa and Bidy for their time, dedication and leadership, and for the contribution they made to our organisation in their tenures on the Board. We are delighted to welcome Dr. Richard Thurlow as the new Chair of Hospice NZ, along with Jeff Bennett and Bill Taine as new Trustees.

We hope you enjoy this issue of the eNews.

Warm regards,

**Mary Schumacher**  
Chief Executive,  
Hospice New Zealand



### Hospice New Zealand

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### HOSPICE AWARENESS WEEK

Raising awareness of hospice services in a society reluctant to talk about death and dying is no easy feat. Yet, death is a natural part of life, and so it is vitally important that New Zealanders are aware of the work of Hospice, and of the ways in which we can help people with life-limiting conditions to live well until they die, whilst supporting their families and whānau.

This week is **Hospice Awareness Week** – a national campaign profiling and celebrating the services that hospices provide in their local communities, and addressing the misconceptions that people sometimes have around hospice care. Across the country, hospices are reaching out and engaging with their local communities in a range of initiatives this week – from ‘pop-up cafes’ in hospice shops to information evenings, community tables, special events and via social media.

Jenny Blyde, a Counsellor at Hospice Taranaki, says, “*The connotations that people often associate with the word ‘Hospice’ can overshadow the enormous benefits that hospice can offer them and their families at a challenging time in their lives. That’s why it’s so very important to talk about what we do, and how we can help.*”





**Hospice care is free of charge for patients and their families**



Hospice Awareness Week  
14 May – 20 May 2018  
www.hospice.org.nz



**Hospice cares for people in any place they call home**



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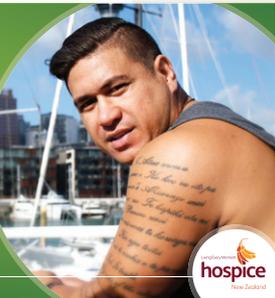
**Hospice is not just a building; it is a philosophy of care**



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**Hospice helps people live every moment, in whatever way is important to them**



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*“Having these conversations and raising awareness today can save a lot of unnecessary stress for families in the future. Finding out that hospice care is free of charge, for example, often comes as an absolute relief for people. They find out there is someone they can ask for help – that Hospice can assist people, not just in a medical sense, but in all sorts of ways. We can help people navigate WINZ and other agencies, for example, to ensure they’re receiving the support they’re entitled to. Or we can help people by organising transport to appointments. Hospice walks alongside each and every person, considerate of their unique and individual needs, simply making the journey smoother.*

*Instead of feeling overwhelmed, people can just get on with day-to-day living and enjoying their lives. Hospice Awareness Week challenges people to revisit their perceptions of hospice, and that makes them more open to finding out how hospice can help them and their families when they need us.”*

Each year, Hospice NZ works with member hospices to help spread the word about hospice care across the country. This year, we’re focusing on the following key messages;

- Hospice care is free of charge for patients and their families
- Hospice cares for people with any life limiting condition
- Hospice is not just a building; it is a philosophy of care
- Hospice cares for people in any place they call home
- Hospice helps people live every moment, in whatever way is important to them.

Mary Schumacher, Chief Executive of Hospice NZ, says “A third of all people who die in New Zealand are supported by hospice. We care for people with a wide range of life limiting conditions, and we are reaching a more diverse range of ages and ethnicities than ever. Yet, we still have a long way to go. The more we can raise awareness of hospice services, the bigger the impact we can make in ensuring the hospice philosophy is incorporated into all areas where palliative care is delivered.

*This Hospice Awareness Week, I warmly encourage you to support the efforts of your local hospice by attending and supporting their events, sharing our key messages with your networks on social media, and by having courageous conversations with your friends and family as to your own wishes when it comes to end of life. Just talking about death and dying, and the role hospice can play in helping you and your families to ‘Live Every Moment’, can make all the difference. Our sincere thanks for your support.”*

# HOSPICE SERVICES IN NEW ZEALAND THE BIG PICTURE

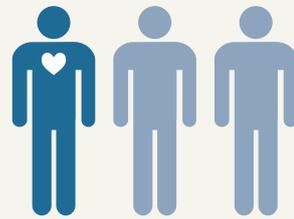


We acknowledge all the patients, families and whānau who are represented in this national picture of hospice services for 2017. We have created this snapshot of services based on FY2017 data supplied by New Zealand hospice services.

# 18,364

families were supported by hospice

Hospice services are for the person living with a life limiting condition and their family and whānau both before and after the death of their loved one.

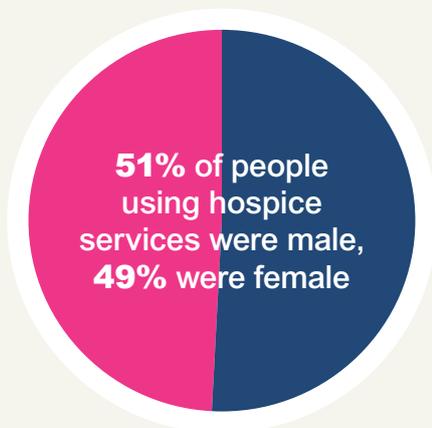


# 1 in 3

people who died in New Zealand were supported by hospice

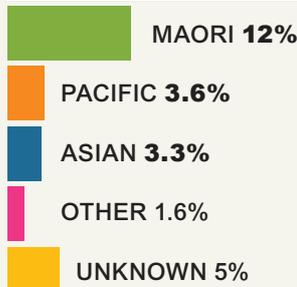
# 30%

of people using hospice services had a non-cancer diagnosis such as respiratory disease, end stage kidney disease or dementia. Many people are not aware that hospice can provide support for people with any life limiting condition.



51% of people using hospice services were male, 49% were female

EUROPEAN 74.5%



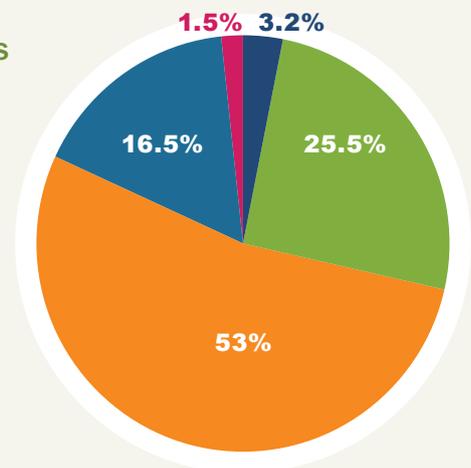
# 103

different ethnic groups were identified by people using hospice services

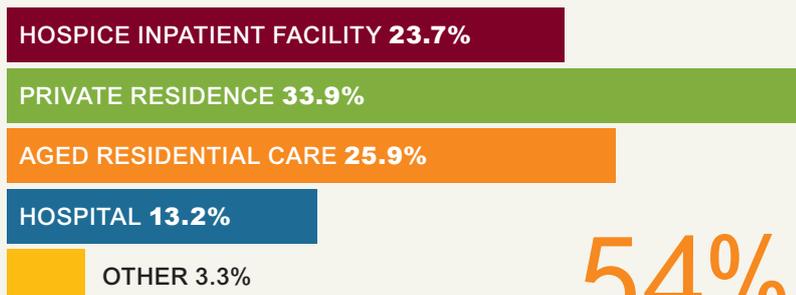
## People of all ages use hospice services

In 2017 just over half of all people using hospice services were aged between 65 & 84 years

- Under 40
- 40-64
- 65-84
- 85-94
- 95+



Where do people using hospice services die?  
During 2017 **10,029** people died supported by hospice.



# 54%

of people using hospice services who identified as Māori died at home in the community

In 2017 more than **12,000** people volunteered their time to work in a variety of roles.

Most people gave their time working in the 125+ second hand shops around the country which raise funds to ensure services remain free of charge. In total over **1.5 Million hours** of time were donated by the volunteer teams.



# LEADERSHIP

## Hospice New Zealand

Mary Schumacher  
**CEO**

Rachel Wilson  
**Communications Manager**

Mandy Gill  
**Executive PA**

Chris Murphy  
**Project Leader**

Hadley Brown  
**Policy and Advocacy Manager**

Moira Marcroft  
**Corporate Partnerships**

George Booty  
**Projects Coordinator**

Ria Earp  
**Advisory – Māori Services**

## The Hospice New Zealand Board 2018

Dr Richard Thurlow (PhD) (Chair)  
**CEO, Waipuna Hospice**

John Peters (Deputy Chair)  
**Chair of the Board,  
Nelson Tasman Hospice**

Peter Buckland  
**CEO, Mercy Healthcare**

Jeff Bennett  
**CEO, Lake Taupō Hospice**

Bill Taine  
**Trustee, Hospice South Canterbury**

## Clinical Advisors to Hospice NZ Board

Dr. Brian Ensor  
**Director Palliative Care,  
Mary Potter Hospice**

Wayne Naylor  
**Director of Nursing,  
Hospice Waikato**

## Community Hospice Network

There are 34 hospice services across New Zealand, and while many hospices provide both inpatient facilities and community-based care, others are solely community-based services; caring for people in their homes and providing support for those in aged care residential facilities and hospitals.

Hospice NZ has formed a special networking group of Community Hospices to connect these smaller services, creating and facilitating opportunities for them to share and support each other throughout the year.

Davina Reed, Operations Manager of Far North Community Hospice, says the Community Hospice Network is a welcome initiative. *"While many issues are universal for all hospices, some opportunities and challenges are especially pertinent to community-based hospices such as ours. Issues such as rural isolation, travelling distances for nurses and raising awareness of home-based care, for example, are challenges particularly relevant to our day-to-day operations. The Community Hospice Network helps us to stay connected, build relationships and share ideas and resources. Hospices working together like this is advantageous on so many levels."*

The group includes services such as Rotorua Community Hospice, Hospice Tairāwhiti and Franklin Hospice.



# Aukahatia

## Fostering Resilience

**23rd Hospice New Zealand Palliative Care Conference**  
19-21 September 2018 / Auckland, New Zealand

### International Keynote Speakers

#### Sue Hanson

National Director of Clinical Services at Calvary, Australia.  
Co-Chair of the NSW Agency for Clinical Innovation (ACI)  
Palliative Care Network.

#### Prof John Swinton

Professor in Practical Theology and Pastoral Care and  
Chair in Divinity and Religious Studies at the University  
of Aberdeen. Honorary professor and researcher at  
Aberdeen's Centre for Advanced Studies in Nursing.  
Founded both the University of Aberdeen's Centre  
for Spirituality, Health and Disability and University's  
Centre for Ministry studies.

#### Prof Max Watson

Director of Project ECHO at Hospice  
UK, London. Visiting Professor at  
University of Ulster and St. Margaret's  
Hospice Taunton, and Honorary Senior  
Lecturer at Queens University Belfast.  
Author and editor with OUP including  
the Oxford Handbook of Palliative Care.

### New Zealand Keynote Speakers

#### Dr Lucy Hone

Director of the New Zealand Institute  
of Wellbeing & Resilience. A research  
associate at AUT University, a published  
academic researcher, author and  
blogger for Psychology Today.

#### Liese Groot-Alberts

Presenting the Sir Roy McKenzie  
guest lecture.

**Aukahatia  
Fostering Resilience**  
is the premier palliative  
care Conference on the  
New Zealand calendar  
in 2018 and is a must  
attend for any healthcare  
professional involved in  
palliative care.

Aukahatia honours and  
reinforces the importance of  
strength and resilience when  
it come to the end of life.  
Strength and resilience is  
essential at an organisational  
and community level for those  
providing or using palliative  
care services.

During Conference 2018  
delegates will be reminded  
of the importance and need to  
be part of a strong team and  
community to provide excellent  
end of life care to patients their  
families and whānau.

Follow the conference on Facebook 

**EARLY BIRD REGISTRATIONS  
CLOSE FRIDAY 29 JULY!**



# WORKFORCE CAPABILITY



Thanks to Cancer Research Trust New Zealand, Hospice NZ is able to offer free weekly palliative care lectures in 2018. This education opportunity is designed for healthcare professionals with an interest in palliative care.

The lectures are delivered via teleconference on the first Thursday of every month, from 7.30-8.30am at registered sites. For information on attending these lectures and catching recordings of some of the lectures you may have missed, visit [www.hospice.org.nz](http://www.hospice.org.nz).

## Upcoming Lectures

**JUNE 7**

### Complex pain management: the old and the new.

Dr Ross Drake, Consultant, Paediatric Palliative Care and Complex Pain Service, Starship Hospital, Auckland

**JULY 5**

### Spiritual care for people with dementia.

Professor John Swinton, Professor in Practical Theology and Pastoral Care; Honorary Professor of Nursing in the Centre for Advanced Studies in Nursing and Chair in Divinity and Religious Studies, University of Aberdeen

## BNI Scholarship Programme

Last year, BNI chapters across the country collectively raised a phenomenal \$195,000 in support of the work of their local hospices. Since our national partnership with BNI New Zealand began in 2007, BNI has generously raised and donated over \$1.6 million to help ensure hospice care remains free of charge.

As part of this very special partnership, BNI New Zealand is proud to support the *BNI Palliative Care Scholarship Programme*, assisting hospice staff to undertake postgraduate study in their specialty fields and grow as leaders in palliative care. Over the years, BNI New Zealand has donated more than \$149,000 to fully fund the programme.

Hospice Social Worker, Mary James, is one of 12 scholarship recipients to benefit from the programme this year. With the support of BNI New Zealand and Nelson Tasman Hospice, Mary is working towards her Masters in Health Science. *"My thesis explores the strengths that underpin and sustain people caring for a loved one who is dying",* says Mary. *"Often there's a tendency to focus on the toll that caregiving takes on families – how difficult it is. There's no doubt it can be challenging, yet what I also see in my practice are some extraordinary positives, which help explain why families often choose to disregard the challenges and care for their family member anyway. Focusing on the strengths that underpin caregivers helps Hospice best develop a kete to support them."*

In Whakatane, BNI's support is helping Hospice Social Worker and Counsellor, Di Watkins, explore ways to support people with 'complicated grief'. *"At some time in our lives, we all suffer loss - but we don't all experience or process grief in the same way,"* says Di. *"Sometimes grief can get 'stuck' over time - something gets in the way of our capacity to heal and it can be devastating and paralyzing. Through my post-grad studies at the University of Auckland, we're exploring ways to better help people who are navigating this challenging time of their lives. It's about walking alongside the person to help them redevelop a sense of control while also giving them the time and space they need to heal."*

Both Mary and Di share their learnings with their Hospice colleagues on an ongoing basis, helping to ensure New Zealand hospices stay at the forefront of palliative care. Hospice NZ Chief Executive, Mary Schumacher says, *"Hospice care is unique in that we care for the 'whole person' – which means physical, spiritual, emotional and social needs are equally important. With BNI's support for our Allied Health professionals through the scholarship programme, together we are ensuring there is a highly skilled workforce committed to caring for people in the best possible way as they approach the end of life. We are sincerely grateful to BNI for their commitment to the philosophy of 'Givers Gain' and the work of Hospice."*



## FUNDRAISING FOR SUSTAINABILITY

### Quest for a Cause

Quest Apartment Hotels is a valued supporter of Hospice NZ, a relationship that began in 2014 when Hospice NZ was selected as the charity partner for their 'Quest for a Cause' programme.

Across the country, Quest Apartment Hotels provide local hospices with discounted, top quality accommodation, and support hospices in raising funds and awareness of our services in the community. Each year, the *Quest Weekend Away* initiative sees accommodation packages generously donated to local hospices for use at fundraising events, and in raffles and auctions.

Sandy Inwood, Fundraising & Events Coordinator at Marlborough Hospice, says "This year we were given a fantastic weekend away for two at Quest Christchurch. We are raffling this prize over Hospice Awareness Week – people love getting away for a weekend break and Quest Weekend Away packages are always a hit. Support like this makes a real difference to us in raising funds and awareness for our services".

We are very grateful for the contribution of this very special company.



APARTMENT HOTELS

### The Great NZ Tractor Trek 2018

When Phil Aish's beloved wife Janice died a year after being diagnosed with cancer, Phil organised a cavalcade of vintage tractors, jeeps and trucks to trek from Bluff to Cape Reinga, raising funds and awareness for hospice services across New Zealand. The first 'Great NZ Tractor Trek' took place in 2016, capturing the hearts and attention of people across the country. In fact, it was so successful, that in 2018, Phil and his dedicated, inspiring crew took on the challenge once again.

Leaving Bluff on the 12th of February, the team were on the road by 8 o'clock each morning, travelling over 2,600km in total in 26 days. Some of the drivers and supporters accompanying Phil were participating in the trek in memory of their own loved ones, as well as to raise funds and awareness of the work of hospice.

Driving rain, washouts, roadworks and even a cyclone could not stop this group of adventurers. Highlights of the trek included parking the tractors outside Parliament Buildings, taking some MP's 'for a spin', and of course the opportunity to appreciate New Zealand's beautiful scenery.

Phil and his team were blown away by the welcome and support they received from local communities along the way. They sincerely appreciated the efforts of hospice staff and volunteers, and the community and church groups, schools, businesses and individuals who supported the trek by way of donations, sponsorship, baking, accommodation, free services and much more.

The two Great NZ Tractor Treks have raised a combined total of more than \$130,000 for New Zealand's hospice services. Hospice NZ assisted Phil with marketing and PR for the event, and together with the efforts of hospices across the country, the Tractor Trek generated an enormous amount of media coverage – raising awareness of our services online, in print and on national radio.

Phil, we are in awe of your wonderful tribute to Janice, and we are so very grateful to you and everyone who has been involved in The Great NZ Tractor Treks. Thank you all for your kindness and your generosity of spirit, and for the incredible contribution you have made to Hospice.





# ADVOCACY

## Some common terms explained

**Palliative care** – care provided by health care workers for people who are dying. Support is also provided for the family and whānau of that person. Physical, spiritual and emotional needs are all equally important.

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**Euthanasia** – when a doctor intentionally ends a person's life, following their request to die.

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**Assisted suicide** – when another person helps someone to commit suicide.

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**Physician Assisted Suicide** – when a doctor assists a suicide, for example, by giving someone a prescription for drugs so that person can commit suicide.

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**Non-treatment decision** – when someone decides not to have any medical treatment, for whatever reason, as is their right under New Zealand Law.

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**Palliative sedation** – when someone is given medication for pain or other difficult symptoms, to relieve suffering and give comfort, making them less aware and unconscious. Palliative sedation is discussed with patient, family and health providers. It is important to have all involved agree to and understand the reason for palliative sedation is to manage symptoms, not to hasten death.

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## Euthanasia – Unsafe and Unnecessary.

In December 2017, ACT Leader David Seymour's End of Life Choice Private Members Bill was drawn from the Parliamentary ballot. This and subsequent support from our Parliamentarians has seen the Bill proceed to the Select Committee stage, with the Health Select Committee calling for public submissions earlier this year.

At last count there were 34,000+ submissions received by the Health Select Committee – the largest public turnout to this type of process for any Bill put before Government. This is a very real demonstration of the interest New Zealanders have in the topic of euthanasia and end of life choice – from both perspectives.

As an organisation caring for over 18,000 people and their families every year, the potential for euthanasia to become legalised in our country has huge potential impact and is of great concern for several reasons.

Hospice NZ took the opportunity to share the importance of access to good palliative care for all, how hospice and palliative care can and does help people at the end of their lives, and our specific concerns about the proposed Bill via our own Submission to the Health Select Committee.

There are several underlying principles of the proposed Bill that cause great concern to our organisation and the clinicians who work with patients and families daily.

### The concept of unbearable suffering

A criterion to quality for euthanasia under the proposed Bill is around "experiences unbearable suffering that cannot be relieved in a manner that he or she finds tolerable". Suffering and tolerance is entirely subjective and deeply personal and therefore cannot be determined by testing. What one person might find unbearable, another person lives with daily, for example, assistance with showering, toileting, dressing, or people who are unable to walk unaided or communicate verbally.

In our experience working alongside people at the end of their lives, we know that suffering varies from day to day and sometimes hour to hour. A request for death as the solution to suffering is an opportunity to discuss concerns and fears that underpin that request and put support in place to address the underlying reason.

### Family decision making and autonomy

We know that families come in all different shapes and sizes, with individual ways of working together as a unit. When someone is unwell and, in these circumstances, living with a terminal illness, family members often play an integral role in the care of that person.

A huge part of what hospice provides is geared towards supporting those family carers in practical caregiving skills, emotional and social support, and grief and bereavement counselling.



## Some common concepts explained

### Is giving someone a syringe driver (morphine) euthanasia?

No, when a patient is given a syringe driver that delivers morphine/pain relief, the purpose is to relieve pain and control symptoms to take away their distress. With euthanasia, the intention is to end the person's life.

### Does active and passive euthanasia exist?

No. It is important to realise that all euthanasia is active; it is a deliberate act to end a person's life.

### We've been told "there is nothing more we can do."

There is always something that can be done. Palliative care is provided up until the very moment a person dies and beyond when it comes to bereavement support for family and whānau. Palliative care does help people with pain and other distressing symptoms – a lot can be done for a person's physical, emotional and spiritual wellbeing.

### Palliative care is active treatment

End of life care does not mean doing nothing and just letting someone die. It is not about "giving up" – it is about "being with" the person. Stopping a treatment doesn't mean no treatment; palliative care is very active total care. Excellent pain control continues to the end and emotional, spiritual and social wellbeing are ever present.

Unfortunately, in the proposed legislation there is a risk that the caregivers or loved ones of someone who is dying will be unaware a request for euthanasia has been made. In the proposed Bill, the consulting doctor is asked to encourage the person to talk with their family, friends and counsellors, but also ensure they know they are not obliged to talk to anyone. As mentioned previously – the request to die can be a pivotal moment to seek additional support or address concerns that have motivated their loved one, without knowledge of the request family members will be left out of crucial health care decisions. This is incredibly important from a cultural perspective as we know that many Pasifika cultures make decisions as a family unit, the same can be said for Māori whānau.

### A terminal illness that is likely to end his or her life within six months

When does the choice to die become the duty to die? A person living with a terminal diagnosis 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, whānau 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 if this is a legal choice available to them.

In Oregon, where euthanasia is legal, the most common reason for assisting suicide are social/existential rather than medical – 49% fear being a burden to family, friends or caregivers<sup>1</sup>.

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<sup>2</sup>.

### Doing our best to ensure a person is free from pressure

It is difficult to detect coercion from behind a closed door. A true picture of the situation motivating the request may not be clear to the doctor responsible for "doing his or her best".

New Zealand has a well-documented incidence of elder abuse. Age Concern reports it receives more than 2000 cases of elder abuse each year, and over 75% of cases involve psychological abuse<sup>3</sup>.

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 and location.

<sup>1</sup> Oregon Health Authority, Public Health Division, Death with Dignity Act, Data Summary 2016

<sup>2</sup> Gerber ML. The incidence of diagnostic error in medicine. BMJ Qual Saf 2013.

<sup>3</sup> [www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ\\_Public/Elder\\_Abuse\\_and\\_Neglect.aspx](http://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ_Public/Elder_Abuse_and_Neglect.aspx)