

# **DYING BADLY**

## **NEW ZEALAND STORIES**

**Compiled and Edited by**

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**The End-of-Life Choice Society of New Zealand Inc**

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**The End-of-Life Choice Society of New Zealand is a voluntary not-for-profit organisation established to lobby for a law change to allow medical aid in dying (MAID) for people suffering a terminal illness or an irreversible condition making life unbearable.**

**It does not advocate breaking the law, though believes that current legislation prohibiting medical assistance to die is unethical and should be changed.**

**At least three-quarters of adult New Zealanders favour a change in the law, according to scientifically-conducted opinion polls. And nearly 9000 people signed the Society's petition calling on Parliament to "investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or irreversible condition which makes life unbearable".**

**After receiving more than 21,000 submissions, the Health Select Committee produced a woeful report with a 630-word "Conclusion" heavy with innuendo and misinformation and lacking recommendations.**

**Many of the submissions included heart-rending stories from relatives and friends of people who suffered agonising and cruel "bad deaths" that were in no way alleviated by hospice or other palliative care.**

**We have extracted a small number of these accounts for this book to maintain the public debate. We are confident that in time our compassionate society will demand that justice prevail and New Zealanders will acquire the ultimate human right of the 21st century – the right to die with dignity.**

**“We do not let animals suffer a long time in unbearable pain without intervention...New Zealanders should not have to suffer either.”**

**“I saw Dad’s primary care physician cry when he asked her why there wasn’t anything she could do to end his suffering.”**

**“My father moaned like an animal for days and kept reaching his arms out.”**

**“We will never be able to get those memories of his suffering out of our minds.”**

**“I cornered one of the nurses and demanded that she do something. She burst into tears. ‘My husband and I have a smallholding,’ she said, ‘and if we allowed our animals to suffer as people suffer here, we’d be sent to jail’.”**

**“The long-lasting memory I have engrained in my brain is the suffering they endured over weeks until their bodies were overtaken from disease. That is not humane or right.”**

**“Denying people the choice of medically-assisted dying in cases such as this is cruel and has no place in a civilised and enlightened society.”**

**“I have heard it said many times that with good palliative care, there is no pain and suffering for the patient – but the reality is that there most certainly is.”**

## Prologue

**“I don’t mind dying as long as I am not there when it happens”  
Woody Allen**

**“With modern medications available today no patient has to ‘be there when it happens’ and thus not need to suffer a terrible and sometimes protracted death.”  
Dr Lannes Johnson**

At least three-quarters of adult New Zealanders want criminal laws changed to allow the terminally ill to end their intolerable suffering with a medically-assisted death, as demonstrated persistently by scientifically-conducted opinion polls.

This would enable them to die peacefully and painlessly at a time of their choosing in the company of family and friends after a loving farewell.

Ten jurisdictions in Europe and North America with a total population of more than 110 million now have laws permitting medical assistance in dying (MAID). The American state of Oregon has allowed it for 20 years and there have been no official complaints that its strict safeguards protecting the old, disabled and vulnerable are not working.

Closer to home, the government of Victoria is the first Australian state to change the law, vowing that its 68 separate safeguards ensure the safest and most conservative MAID legislation in the world.

New Zealand, once a nation of pioneering enlightened legislation and social justice, is on the wrong side of history on this issue. The law will inevitably be changed. It’s just a question of when and how many more people will have to die badly before our legislators see the light.

It has been 31 years since New Zealand adopted homosexual law reform, prostitution was decriminalised in 2003 and same sex marriage was legalised four years ago.

Parliament has debated Death with Dignity Bills twice and the trend is apparent. In 1995, it was defeated heavily by 61 votes to 29. In 2003, it failed by just two votes, 60-58.

Nearly 9000 people signed the End-of-Life Choice Society’s petition calling on Parliament to reconsider the issue and over 21,000 made submissions to the health select committee. The fact that 80 percent of them opposed law reform is neither here nor there. As the opinion polls show, that did not reflect the national feeling - fundamentalist religious zealots have always been good at whipping their followers into mass protest action and it is not a numbers game anyway.

The committee, deliberately choosing to mislead the uninformed by equating medically-assisted dying with youth suicide, ignored the facts put before it, declined to travel overseas to get first-hand experience of how it works – unlike a similar inquiry in Victoria - and elected to make no recommendations.

Opponents frequently claim that a law change is unnecessary because palliative care, especially in a hospice, ensures that the sick die peacefully and painlessly.

This is not true and we have taken just a few of the “bad deaths” reported in submissions to the committee to refute the claim.

As these accounts reveal, terminally ill New Zealanders die daily in cruel suffering unimaginable to the healthy and those who have not witnessed bad deaths among friends and relations.

This book is not intended as a criticism of New Zealand's palliative care services or the dedicated doctors and nurses who give of their best. Rather, it reveals what happens despite their efforts.

Nevertheless, some of these professionals need to be more aware of what they perhaps are not seeing - the time until patients get to them; the inexperience of various doctors and nurses not fully trained in palliative care, e.g. those attending patients in rest homes; the Catholic and other ideology so opposed to MAID in principle; and the fact that patients do not always want to be sedated for days at the end of their life.

The EOLC Society fully supports extra funding and support for palliative care and hospices, but would see MAID integrated with palliative care as a choice at present unavailable except outside the law.

These are edited extracts from the submissions which are all in the public domain as they have been posted on the Parliamentary website. We endeavoured, however, to get permission from the submitters to reproduce their stories and those whose names are used all gave their approval. Where it was not possible to contact the writers of accounts we thought should be published in the wider public interest, we print them with their initials.

**Dr Jack Havill  
David Barber**

**Wellington, December 2017**

**Cover painting: Jack Havill  
Cover design: Stefanie McKnight**

## Foreword

People die cruel, agonizingly painful, deaths in New Zealand every day. Although the end comes quickly for a few, many suffer horribly for days, some for weeks, while others linger at death's door for months waiting for merciful relief.

The law, supported by those who profess religious beliefs that deny end-of-life choice (EOLC) for all, says that is as it should be.

Thousands of people who made submissions to Parliament's inquiry into medically-assisted dying do not agree.

They explained why in moving testimony recounting terrible tales of the dying and death of family members and friends in conditions that a number observed would provoke criminal charges if the sufferers were animals.

They told of loved ones pleading for help to die and end their misery - help they knew they had to deny or risk a 14-year prison sentence. They told of being haunted by nightmare recollections of the plight of once strong, lively, independent, men and women reduced to human shells, dependent on others to feed, toilet, wash and succour them.

Above all, they told of the heart-breaking loss of dignity – “the state of being worthy of honour or respect”, as the dictionary defines it - that every human holds dear throughout their life.

Parliament's Health Select Committee had been asked to “investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or irreversible condition which makes life unbearable”.

The outcome of its two-year inquiry made little effort to acknowledge the terrible tales submitted to it, with only passing references to pain and suffering and the effect on families of watching loved ones die a painful death.

It also ignored the fact that at least three-quarters of New Zealanders want a law change to allow medical assistance in dying for the terminally ill, as repeatedly shown by scientifically-conducted opinion polls.

The committee skewed the inquiry right from the start when formulating its own terms of reference to say its task was “to undertake an investigation into ending one's life in New Zealand”.

It was not. The introduction of this element led to lots of confusion in many submitters who were unable to distinguish between “irrational suicide” and medical aid in dying (MAID). The committee's chairman himself had the same problem, as demonstrated when he used the word “suicide” no fewer than 11 times in an article in the *New Zealand Herald* after releasing its report.

Some submitters thought that legalisation of assisted dying might encourage irrational suicide. There is absolutely no evidence for this in any jurisdiction that has introduced enlightened laws to allow MAID, including the American state of Oregon, where it has been legal for 20 years.

As Shirley Seales, mother of brain cancer victim Lecretia who bravely but unsuccessfully sought a judge's permission to end her suffering in 2015, told the committee: “This is not people choosing whether to live or die as is the case in suicide but terminally ill people who have no

choice about whether they will continue to live, having the right to choose how and when they die.”

Opponents of a law change could ponder why New Zealand has such a high suicide rate, especially among young people, when we have not legalised assisted dying.

Cases of suicide occurred in some submissions included here, and most were terminally ill patients who suffered agonising deaths over days and even weeks after refusing to eat and drink to hasten their demise because nobody could help them without risking a 14-year prison sentence.

On the other hand, there were many heart-breaking accounts of “bad deaths” of family members and friends, denied the choice that would have given them a peaceful pain-free end in the company of the people they loved. This book contains just a fraction of them – less than five percent.

Opponents of medical assistance – frequently people who have not experienced seeing a loved one suffer a bad death – claim that it is unnecessary because palliative care in a hospice environment can stop all suffering and guarantee a peaceful passing.

These stories put the lie to that, with medical practitioners and nurses, including those with palliative care experience, testifying to the contrary.

Some describe situations where doctors and nurses failed to give enough drugs to stop suffering, because of their ideology or fear that patients would die as a result – an outcome the patients and their families desperately wanted.

Many submissions described harrowing heartache of relatives and friends who watched loved ones suffer even in a hospice. They told of being haunted by nightmare flashbacks years later, cruel repeated visions that time could not heal.

The number of stories of patients pleading to both health professionals and relatives for help to die and inevitably being denied in accordance with present law, refute claims by some experienced palliative care doctors that they do not get such requests.

Bets Blake, of Kaukapakapa, who nursed for 52 years, told the committee: “There were times when myself and other staff members were asked ‘Please help me die’, or ‘Can't you just give me something so I can go to sleep and not wake up?’ Or ‘Nurse, I have suffered enough, please someone help me’.”

She added: “...not all suffering is relieved in palliative care and not all pain is, or can be, relieved. I nursed many patients who experienced intolerable physical and emotional suffering and those were in intolerable, intractable pain.”

It is obvious from these accounts that palliative care standards are very patchy and facilities are not readily available to patients, especially in rural areas. It is also clear that there is an acute shortage of experienced doctors and nurses in rest homes, where the death rate is more than four times that in hospices.

Dr Lannes Johnson, an Auckland GP and palliative care specialist now retired in Russell, told the committee a growing number of people were dying in rest homes and other residential care facilities (RCF) where “many patients die a horrible death”.

Patients who are dying, or expected to die of age related conditions, severe chronic disease or multiple long term comorbidities and experiencing, or expected to experience, unbearable pain, discomfort, or distress of a profound nature, are different from younger people who may request ‘assisted suicide’ for a variety of reasons,” he said in his submission.

“These, usually elderly, patients, have no potential for any independent, ‘normal’ life; their life is in effect over.”

He said deaths in RCFs had risen from 33 percent of all deaths in 2000 to 40 percent in 2013 while patients dying in hospices (5.7 percent in 2013) had not increased greatly.

Dr Johnson told the authors of this book in an email: "Looking at the trend...one can extrapolate that soon 80 percent of deaths in New Zealand will be in rest/retirement/nursing homes/private hospitals."

He said that was a worry because there is no onus on the private establishments to ensure that doctors caring for the patients are trained in palliative care and there were not enough specialists in either hospices or hospitals to provide full 24/7 services.

Dr Libby Smales, a Hastings palliative care physician who has worked with thousands of dying patients and their families over decades, agrees. She told the committee her initial belief that good hospice/palliative care (H/PC) would address all the needs had proved "merely a dream".

She said: "Not only is access to H/PC services in NZ, patchy and the services variable in quality, figures released from an Australian study widely quoted this year show that 10-20% of patients on Hospice programmes experience unbearable pain/suffering as they die. We do not have figures for those who cannot access H/PC."

Dr Johnson said it was very difficult for GPs to deliver adequate end-of-life care anywhere other than when people were dying at home. "Under the present law there are too many conflicting views with rest homes' staff and managers are concerned to keep patients alive as long as possible - it costs to fill a vacant bed."

In his submission, he told the committee: "If terrible deaths continue to occur in RCFs, then NZ does face a terribly large problem, one that is likely to cause a public backlash and condemnation of the medical and nursing professions."

"It would be relevant to examine institutions that remunerate doctors on a fee for service basis – I have had experience of facility managers preventing doctors reviewing patients in order to save money and I am uncomfortable with facilities who view longevity of their residents as helpful to finances."

Dr Johnson said: "In RCF dying patients may not be administered the full doses of medically prescribed drugs as mistakenly nurses may not recognise distress unless pain is present. In many cases the other forms of distress are not recognised."

He cited American film maker Woody Allen's famous quote: "I don't mind dying as long as I am not there when it happens" and added: "With modern medications available today no patient has to 'be there when it happens' and thus not need to suffer a terrible and sometimes protracted death."

Dr Smales said the current debate about MAID in New Zealand medical circles was remarkably similar to that in the 1980s when some struggled to establish H/P C.

"The fears around H/PC were that we might be engaged in 'bumping people off', particularly the vulnerable/ unwanted; that everyone would be filled up with morphine until they died; and from the Catholic Church particularly, issues to do with the ethics of interfering, i.e. possibly ending lives prematurely, the sanctity of suffering and 'slippery slopes' - a scary term bandied about and never clarified."

"These fears were/are demonstrably fears not facts. Over quite a short time the value of H/PC became recognised and gratefully accepted. It took a while longer and much lobbying for this recognition to be followed by any sort of funding, and these services are still relatively under-funded."



Dr Smales said underfunding was relevant today and there is a global shortage of well-trained H/PC staff, with many unfilled positions in New Zealand and hospice teams stretched. “We have an aging population, medical advances have produced many more possible interventions which are often amazing, but sometimes prolong existence rather than life and unintentionally increase suffering.”

She said in legislations where EOLC was legal, referral to a hospice programme was a mandatory part of the process. “This deals with concerns about the diagnosis and management of the terminal condition and clarifies whether treatable depression is a motivation or not.

“As a result, H/PC funding has improved and so have the range and quality of the services offered - proving that H/PC and EOLC can be mutually beneficial.

“Initially, I believed that the heart-breaking stories I heard of unbearable suffering while dying would be heard no more if H/PC was good enough and available to everyone who needed it. The difference good H/PC can make is often dramatic and life changing.

“However, it did not take long for us to realise that even with the best skills and care available, some disease processes were/are intractably unresponsive to all therapeutic interventions. It is not always possible to fix all pain and suffering especially with a conscious patient.

“This raised the question of Terminal Sedation, (i.e. using medication to maintain an unconscious/peaceful state until death) with the attendant issues of the ethics involved and our own sense of failure. There was much discussion globally, reaching a consensus that as the intention of hospice care is to alleviate suffering, not to shorten life, sedation, in this context is compassionate, legal and ethical.

“The reality is, that for the small number of patients who need sedation for the last few hours or days of their lives, it makes a significant and valuable difference to those dying and those who have to go on living. Terminal sedation is now an accepted option of last resort in H/PC services around the world.”

A number of submitters referred to family members who suffered Alzheimer’s Disease or other forms of dementia. They usually referred to the tragic indignity of these sufferers and how some committed suicide after being diagnosed – cutting short lives they may have continued had they been assured of a peaceful release when they passed a certain point they had declared before their illness.

The point was made that victims of bad deaths and their families were denied the chance to say goodbye properly because the patient is increasingly sedated to ease suffering, sometimes to the extent of being completely unconscious.

## THE STORIES

I will never forget when my husband Kim told me he had cancer – the moment which froze my heart, took my breath away and terrified me. That was all before I knew what lay ahead of us for the next two years – before I truly knew what it meant to suffer through the horror of chemotherapy and radiation, the fear of rushing him to hospital with a basic infection his body was no longer strong enough to fight and nearly killed him, to battle through the months of pain management, juggling of drugs and the drudge of him not being able to swallow anything for over eight months.

We did have two months of thinking we had beaten this disease – two months when we didn't know it had travelled to other vital organs and places in his body we couldn't simply cut it out of – two wonderful months of hope.

But as he told me: “We simply aren't going to get to grow old together” – all our dreams and hopes gone to a disease that will break your heart in a million ways and then come back for more. Though I knew his death was coming in the next 12-18 months there is no preparing for the end (which ended up being only five months).

No preparing for the immense loss and void in your life. But bigger than that and what I am left truly struggling with on a daily basis since his death three months ago is that final month, days and hours – those are the memories engrained in my brain and on my heart, and that is when I feel I have truly failed him.



No matter how much I told him I loved him, no matter how many times I bent to lift him when his muscles had gone and he couldn't stand or take himself to the toilet, no matter how many nights I lay awake listening to each drawn and difficult breath and when I held his hand in those last 48 hours and managed the final moments my two young kids would see their dad, I had let him down.

When he really needed some peace and dignity – when he so desperately said “ENOUGH!”, I didn’t help him – I couldn’t help him - and that is something I will live with for the rest of my life.

I have no doubt that deciding how someone should be given the choice to manage a life and death is an immensely difficult, sensitive and a complicated question – and it should be. But I equally know it is one we as a society must tackle.

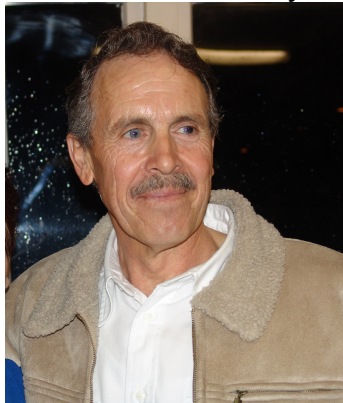
There simply does come a moment in terminal illnesses where there is no hope, there is an utter and total lack of dignity, where there is no quality of life and it is simply an exercise in waiting for your body to give up.

Where final days and weeks have no quality, they simply destroy a person slowly and painfully.

**Liz Fitzgerald**  
**Wellington**

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On 14 October 2015 my father Ivan David Breach chose to end his battle with cancer by taking his own life in a way that ensured he would not accidentally survive. He drove to a secluded spot at Wairere Falls, walked from the car park just off into the bush, placed a rifle to his forehead and pulled the trigger. I choose to believe he died instantly with little pain.



For the past two years he had fought a terrible battle with cancer. Along with part of a lung removed by surgery he also lost his sense of smell and taste and his voice. He was in extreme pain in his chest and throat area and had started to experience seizures. On Tuesday 13 October he was told by his doctor "There is no good news for you, I'm afraid". It seemed the cancers had reached his brain hence the seizures, which were worsening rapidly.

My father was a true Kiwi bloke, builder, glazier, farmer, musician, hunter, fisherman, sportsman, boatie - there was nothing he couldn't do and he did everything well. Strong, quiet and proud he refused to be a burden on anyone and wished to maintain what dignity he had left. To be told that within one month's time he would be dependent on someone for everything from eating, to washing, to dressing was intolerable.

Although us kids and mum would have done anything for him without hesitation, he would not allow this. Losing the use of his right hand and the feeling in his feet he would have known he had to act fast before he was no longer capable of going out on his own terms.

We all understand why he did this and think him the bravest person ever but the thought that he was forced to end his life in this way, on his own and by his own hand, is so very hard to stomach.

At times dad and I had spoken about euthanasia and we all know that if he could have he would have opted for this path which would have enabled us to be there with him, supporting and loving him right to the very end.

He would never consider asking anyone for help for fear of destroying their life as well as his own. With no cure, no chance, no hope and only agony, loss of control, loss of dignity and a slow painful death to look forward to what other option was available to our strong proud Kiwi dad?

Think of his last moments...alone on bended knee with rifle pressed to forehead...we all have to live with that thought forever more.

Voluntary euthanasia in this situation would not lessen our loss and grief which was always inevitable but would remove the guilt, shock and shame associated with a "suicide". It would have enabled my father to end his life in a more dignified manner, less painfully and surrounded by love and support.

**Allison Margret Breach**  
**Pukekohe**

\* \* \*

I nursed a woman who had terminal breast cancer and she suffered a slow painful lingering death because her doctor was of the Catholic faith and refused to offer any extra assistance to my patient or her family who begged for M. to be allowed to die. The doctor asserted it was God's will.

M. begged her doctor to let her go whilst she was still lucid but that was not heeded by her religious doctor. M. believed in a God but after suffering all that pain for months she also screamed and begged to be allowed to die. She suffered to the very end of her life with me by her side.

My brother-in-law cried out in agony from the pain even with the assistance of the hospice when he was dying from liver cancer and it was heart-breaking to watch everyone suffer with him waiting for an inevitable death. Everyone in pain.

My mother died of gangrene at the age of 87. A good age, but a very painful death from leg ulcers that were cruelly painful and we had to sit and watch her pain...crying out constantly...waiting for the gangrene to kill her because her heart kept on beating.

I still wake at night with the nightmare of nights and days and weeks of watching my lovely mother reduced to a morphine-induced zombie waiting for death. My son suffers the same pain from watching his beloved grandmother dying a slow painful death and other friends say they have the same memories of loved ones suffering needlessly when they could have been released from the painful hell by making this legislation.

We live and die like all creatures, but even my cats who lived 19 years deserved to be given an injection when they could no longer eat and life had left them wanting, and they died in my

arms without weeks of suffering. My memories of their deaths are positive and I can bear that. We as humans deserve the same right as animals.

I will walk into the sea and drown myself before I allow my only son to watch me dying a miserable death in agony that will haunt him for the rest of his life as I am haunted by the deaths of my loved ones.

**Raewyn Finlayson**  
**Waiheke Island**

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My 58-year-old father R. was diagnosed with terminal brain cancer in December 2014. I believe that he discussed the end of life with my mother both generally before his diagnosis and specifically following his diagnosis. Though he wanted very much to live, he did not want to die without dignity.

I won't go into a recitation of his symptoms; suffice to say that we watched as his physical and cognitive abilities deteriorated - his personality too was chipped away. I will never be sure how much of Dad was stolen by his disease itself and how much was stolen by his utter desolation at seeing the disease take those abilities away and create significant burdens for his family.

The staff at...Hospice was accommodating, caring and kind during Dad's final months and days. Dad was shown respect and the staff worked diligently to ease his suffering, for which we will always be grateful. The mental distress, however, was worst for both Dad and our family. I heard him say on at least two occasions that he wouldn't let a dog suffer in the way he was suffering. Dad would have chosen to end his life months before he died, if the option had been available to him. I know this from discussions with him.

I cannot speak for the medical profession, but I will say I saw Dad's primary care physician cry when he asked her why there wasn't anything she could do to end his suffering. I don't presume to know what she was thinking, but I do know she liked my dad and hated that she couldn't do more for him.

**A.M.**

\* \* \*

At the time of her death, my mother was 93 years old. Despite her age, my mother had an active and fulfilling life. She was not depressed or down and she had a full and active life. However, neither was she desperate to cling on to life, especially if circumstances arose where she had no quality of life.

She was influenced by witnessing the very unpleasant death of her own mother in 1976.

Over a six month period, she had observed her mother die slowly and painfully as a result of a series of strokes which had left her bedridden and incapacitated, to eventually die from pneumonia after all care was withdrawn (due to its ineffectiveness).

My mother did not want to die that way, and after the death of her mother, she began to investigate ways that she might end her own life if she got to the point where she could no longer bear living.



In 2012 she had obtained two vials of Nembutal from Mexico, over the internet. She was happy to have obtained a painless and quick acting medicine that provided her with comfort that she could control the end of her life. Yet my mother was frustrated and upset that the state of the law meant that, if she elected to end her own life, she could not do so with those she loved around her.

Despite the fact that she did not want to die alone, she was adamant that we could not be present due to the risk of prosecution if we were involved. My mother had often discussed her wish to die without suffering, and told us that she would give us warning if she chose to do so. The exception was if she suffered a stroke, in which case she said she would take her life immediately. She was terrified that, if she suffered a stroke or strokes, she would lose her mental or physical capacity and the ability to control the end of her life.

On 10 or 11 February 2015, my mother took the two vials of Nembutal. She left a note that said: "I have a stroke". We could not be sure of the exact date of her death as we had no warning and we did not know that it had occurred. It was not pleasant for my family to have to discover that she had died.

It seems that my mother realised that she was having a stroke (likely because of some paralysis - her handwriting and grammar in the note she left were also uncharacteristically poor) and decided to take the Nembutal while she was still able.

I have no doubt that, had my mother been able to access the services of a doctor to help her die, then she would not have chosen to end her life as soon as she suffered the first stroke. She would have known that even if she was eventually incapacitated, she would have been able to choose her own passing. Additionally, she would have been able to say goodbye to her family and die surrounded by those she loved, rather than alone.

The fact of my mother's sudden death has been very difficult for my family, as we feel that we have been denied the opportunity to say goodbye properly. It is also very upsetting to know that she had to die alone and without her loved ones around her. I provide this testament to highlight the reasons people like my mother may end their lives earlier than they otherwise would if assisted dying was available.

**Lawrence Cartmell**  
**Wellington**

\* \* \*

... my darling Dad...had a hole in his oesophagus after violent vomiting from food poisoning. It was not picked up early enough so after two weeks we were told he would not get better and that his organs were failing.

They removed all treatment except pain relief. He said he was in pain so I told the nurse and she gave him more relief but again he said he was in pain and again the nurse gave him more but said that was the maximum.

That has angered me to this day because the maximum is when he dies peacefully and painlessly not a one-size-fits-all dosage. Luckily he did not linger too much longer.

...a friend's husband...had prostate cancer and haemorrhaged due to the after effects of chemotherapy. They operated but things were not good. He was in so much pain because the doctor gave him the-one-size-fits all dosage even though he was told that M. had been on morphine for years for injuries due to an accident, so he had built up immunity to it, and spent the next nine hours in agony until he died.

**S.M.O**

\* \* \*

I recently witnessed a loved family member die of cancer. She was 49 years old, there was nothing wrong with her mind but her body slowly and painfully failed her. She had planned to take her own life before things got really bad, but she got to the stage her body wouldn't function and she was unable to do this for herself. She wanted to die in dignity but that was all stripped away from her.

She spent over six weeks in Hospice, the nurses did their best to keep her comfortable, but this was a daily struggle, the pain was awful for her. It was unfair and inhumane. She struggled to breathe which was terrifying.

She was ready to die, she wanted to die, she hated not being able to use her body and she hated the fact her family and friends witnessed her decline.

The nurses informed us that because she was young her non-affected organs were still strong and this prolonged her death.

I believe she should have had the choice to end her life at an earlier stage and die peacefully. If I was diagnosed with a similar terminal illness I would like to have the option to end my life.

**J.P.**

\* \* \*

My mother had suffered immense pain since injuring herself in an accident in a rest home in Auckland. Her bones never recovered sufficiently for her to be able to enjoy the remainder of her life, and her cries for pain relief were met only intermittently and only during the day, therefore sleep deprivation also occurred.

At 80 years of age, she felt she should have been treated with more compassion and effectiveness instead of having to beg for pain-relief. Mum became so angry and frustrated at being forced to suffer the pain that she gradually starved herself to death regardless of rest home staff (and her children's) attempts to get her to take nourishment. Our family would have appreciated access to medical intervention to allow her to die pain free and with dignity.

Forcing people to continue suffering unnecessarily is cruel and inhumane, and amounts to a form of torture and punishment. We do not let animals suffer a long time in unbearable pain without intervention unless the watching human happens to be insane. New Zealanders should not have to suffer either.

**P.P.**

\* \* \*

Lecretia Seales was our precious daughter. Lecretia was brave and could withstand more pain than anyone we have ever known. She never complained and lived each day to the fullest despite the many handicaps and pain she lived with. Having a choice was extremely important to her and we doubt that had she been given the choice, she would have exercised it. It would however have given her peace of mind in the weeks leading up to her death at a time that was already very stressful. She was never afraid to die, believing that she had lived her life as a good person who always looked out for others.



Given the nature of her illness, she had a real fear of losing her mind and she did not consider being drugged to the eyeballs and unable to recognise her loved ones as actually living. We are grateful for the palliative care that Lecretia received and in particular for the assistance that enabled her to remain at home surrounded by her loved ones.

We have listened to the false arguments of assisted dying being a substitute for palliative care. This is completely misguided as both have very important roles to play and are



complementary to each other. It is, however, a lucky dip as to the amount and quality of care available.

I watched my father suffer an extremely painful and prolonged death in an understaffed rest home. There were no doctors visible, the staff, whilst caring, were under-resourced and the whole place reeked of urine. My father moaned like an animal for days and kept reaching his arms out.

Nursing staff were surprised at how long he lingered as he had stopped eating and drinking in the weeks leading up to his death. He had morphine but this was not sufficient to alleviate the pain from the cancer in his bones.

We are aware that some doctors are already practicing a degree of assisted dying by administering large doses of pain relief to hasten the onset of death. Once again this is a lucky dip as to what doctor you get.

We understand the views expressed by those opposed to assisted dying and firmly believe in the strict parameters required to safeguard the vulnerable. The need to ensure the legislation is well drafted should not be an obstacle to granting the right to a choice to have a dignified death.

We are incredibly proud of our daughter for initiating these conversations and our own observations are that there is overwhelming public support for assisted dying.

### **Larry and Shirley Seales Tauranga**



*New Zealand Herald cartoon by Rod Emmerson after Lecretia, who had an untreatable brain tumour, failed in a High Court appeal to secure medical assistance to help her die.*

\* \* \*

This is based on my personal experience witnessing the death of my mother in 2013 (aged 66) from Glioblastoma multiforme – an aggressive and terminal form of brain cancer.

My mother was a social, intelligent, thoughtful person. She, of all her attributes, was most proud of her brain – as was I. Upon diagnosis, she secretly confessed to my father how her

greatest fear would be to lose the function of this most precious organ. Her greatest fears were realised. Over the subsequent weeks she slowly lost her mind.

For five days of unconsciousness I whispered to her she could let go. I'll never be able to fully describe how painful it is to watch fever and infection ravage someone body, to listen to the 'death rattle' for days on end. It is the most traumatic experience of my life – and I'm a resilient person. It is this final event – a person having to be 'killed' in such a way by disease that I want to preserve others from having to witness.

**K.S.I.**

\* \* \*

In January 2015 I received an email from a friend and colleague in her eighties. She was suffering from unstable arrhythmia which was difficult to manage medically and had subsequently developed ischaemic leg pain that she was finding unbearable. Arterial blockage was not amenable to stenting, and amputation was not an option she was prepared to consider.

She wrote in an email, "Unfortunately the new painkillers work brilliantly as such, but I just reacted badly and produced all the side effects you can think of... Since I have been unable to keep any food down since last Saturday, I decided to put forward the plan I had for finally using 'death by dehydration'."

Over the next few days we spoke and then emailed about her plans and the practicalities of implementing them. Although she would have preferred to continue to live, she did not accept death as it came and said she would have liked some choice and control over the timing and manner of her dying. What she really wanted was that her GP to be allowed to assist her to die. Knowing this was impossible, she took the only option as she saw it.

She said to me, "If you know there is a way out, you can focus on what life has to offer. You can balance the pain and suffering because if it gets to that point, you can end it".

She was fortunate that her GP and the nursing home staff were supportive of her choice to refuse all food and fluids, and she was given exemplary end-of-life care. During the last few days of her dying she was never left on her own.

My good friend and colleague died nine days after refusing all fluids and nutrition. Although she exercised her will in determining her death, I believe she died sooner than was necessary if she had had a legal choice for an assisted death.

I still find it distressing that the vibrant, intelligent, generous and loving woman I knew withered away and died of dehydration because she was denied a death that was both dignified and what she wanted.

**Dr Phillipa Malpas  
Auckland**

\* \* \*

My mother is totally reliant on care-givers to survive. Her waking time is spent lying in a chair just looking around the day-room, sometimes holding a doll for comfort. My mother was a strong intelligent woman who played an active part in her community, was involved in sport and was an avid reader. That woman is no longer here.

I do not want to continue “to exist” when my functional capacities mean that I cannot make safe choices for myself. There needs to be a legal option for people - not premature suicide - for whom prolonged care and total dependence is not a tenable option. People have the right to decide for themselves when they have reached the point at which they wish to end their suffering, be it mental or physical.

**Jacqueline Renouf**  
**Paraparaumu**

\* \* \*

My husband died three years ago of multiple myeloma. He died a painful, miserable death and we begged the registered nurses repeatedly for stronger painkillers but were consistently refused and told that he is getting what the doctor has charted.

We as a family watched him writhe in pain, he was confused, very agitated and continually trying to get out of bed as he didn't know what was happening to him and we were powerless to assist him.

He was only given morphine when in desperation I threatened to go to the *Bay of Plenty Times* and expose what was happening. Family stayed with him 24 hours a day for the last 10 days of his life.

It is a trauma I would not wish on anyone and I liken it to being in Vietnam fighting during the war there and suffering PTSD afterwards. We will never be able to get those memories of his suffering out of our minds.

Good hospice palliative care is not always available for everyone. Dying patients are not always able to be relieved of their pain due to a number of different situations and circumstances. My husband had neuropathy in both his legs and feet and renal failure. He was consistently not given correct painkiller medication due we were told to his renal failure but he died a week later anyway.

They were just dragging out the agony. His palliative care was completely botched and I live in terror that the same thing could happen to me or anyone else that I love.

**C.T.**

\* \* \*

My 91-year-old very religious mother, in agony with a disintegrated spine, could no longer move. She was still extremely intelligent and loathed lying in her body waste waiting for busy staff to clean up the mess. She requested no more food or liquid but plenty of morphine.

Her words: "I am not afraid of dying. I just don't want to die in pain."

I sat beside her for 12 days and nights as she faded into a skeleton - my Mum, Kate (Kitty) Audain, became a woman I did not know. After her death, I sunk into bad depression for the first time in my 67 years. The 12 days of watching her fade were just horrific.



Her last 12 days were not beneficial to her, the kind staff who kept turning her, or me. Just a waste of time. She would much rather have gone after a cup of tea and some medicine surrounded by all of us that loved her. There was no dignity in her death sadly. I would so love it to change so I might leave with dignity if I am ever in her position

**Jeanette Audain**  
**Auckland**

\* \* \*

A few years ago, my mother-in-law was admitted to a nursing home in the final stages of ovarian cancer. It was a pleasant place with dedicated, friendly staff. Unfortunately, the doctor overseeing the patients had extremely conservative attitudes on pain relief and Joy was in constant agony. He'd visit once a day and until his word was given, dosage could not be increased.

Angered by this, I cornered one of the nurses and demanded that she do something. She burst into tears. "My husband and I have a smallholding," she said, "and if we allowed our animals to suffer as people suffer here we'd be sent to jail."

I was ashamed at what I'd said. The nurse was just as much a victim of the system she was forced to work under as her patients were. This state of affairs is obscene. All terminally ill people may not be forced to die in this way but so long as the dying are denied choice the risk is always there, either because of the nature of their illness or the attitudes of those in power. Joy is free of pain now but her death left her loved ones with ugly memories they will never forget.

**Simon Johnson**  
**Palmerston North**

\* \* \*

I am a medical professional. My role is a Registered Nurse. My partner died 18 months ago. I was his carer until his death along with support from family. His GP was not adequately trained in palliative care and I had to drive what my partner needed. This was very hard as I was unable to “relax back” safe in the knowledge that the GP would deliver the appropriate care.

The GP did his best but he lacked the required knowledge. Gate-keeping went on between two community services which should have provided facilities to enable me to care for him properly at home. Endless phone calls ensued at a very stressful time. I needed a hospital bed in order to care for him better - was told that had been stopped a year before my partner died. How ridiculous is that when the demand on the health dollar is so huge and community care is cheaper?

If it is government policy to move towards community care then provisions must be made to care for people in their homes adequately. Finally, I received a visit from palliative care but it was too late as my partner had died four hours previously.

I wish to comment from a health professional's point of view: Palliative care needs more funding whether there is assisted dying or not. Rural areas are sadly neglected in this field. Smaller provincial areas are not much better and even the larger metropolitan areas have many gaps in palliative care provision. This occurs for many reasons, some of which are due to delayed referrals, weekend referrals, expertise of doctors and their knowledge base, skill base of district nurses recognising situation for palliative care requirement and resources of palliative care available.

These are a few of the reasons. Even in a large metropolitan hospital referrals to palliative care are delayed. These again occur for many reasons: Gate-keeping among the medical specialties; reluctance on part of medical team to refer because the physician/surgeon is unable to accept “defeat”; need for referral delayed due to weekend and skill base of doctors on duty inadequate; patients themselves or relatives having difficulty accepting the end is near.

People do die in pain in hospital. This again occurs for many reasons. Knowledge base of both doctors and nurses in prescribing and administering adequate analgesia and other adjuvant drugs is one of the main reasons. The busyness of the ward setting; adequate staffing; the disease process of the patient; deterioration of the patient and staff too busy to attend.

From my experience of over 30 years I have witnessed some “good” deaths, but far more unpleasant and undignified deaths.

**L.B.**

\* \* \*

My neighbour's young cousin died this year, aged 24. In spite of Hospice/Palliative Care, her suffering was so terrible that none of the children whom she loved and who loved her, were allowed to see her for weeks before she died, she pleaded for help to end her life. The family are in tatters.

An elderly woman friend, aged 84, highly intelligent, fiercely independent and very determined, suffering intractable pain unresponsive to all the medications she could tolerate, and facing the loss of both legs due to advanced, inoperable arterial disease, ended her life earlier this year by stopping eating and drinking. She reduced intake over several weeks before she finally

declined food and drink, the 10 days it took for her to die after this were long and hard. She accessed H/PC.

Over the last eight years I have watched my very elderly mother-in-law (98 when she died) dwindle to a distressed, deaf, blind, demented, incontinent shadow of her former self.

This dignified intelligent woman suffered painful falls, multiple spinal fractures, a hip replacement, skin grafts, malignant disease, and the endless limitations and degradations of a failing body, before her mind failed her and a final inoperable fractured pelvis ended her suffering, (thank heavens for the terminal sedation supplied by the Hospice.)

I believe that if she had been able to choose to avoid it all she would have. I would definitely choose not to inflict such a burden of care on my children.

Another of my elderly (aged 99) friends, mentally very sharp, blind, with limited hearing and renal failure, a painful, inoperable malignant ulcer on her leg and no friends her own age left, prays every night that she will go to sleep and not wake up. She is much loved and well cared for, she hates it all; she hates being trapped in her failing body. She aches to leave it.

I do not want such suffering for myself, for my children or for anyone, unless they so choose. My personal and professional experience over decades has convinced me that leaving it all to chance is foolhardy. H/PC is not always available or enough.

I believe each of us deserves the right to peace of mind - the legal right to be able to choose a peaceful death. My life, my death, my choice.

**Dr Libby Smales  
Hastings**

\* \* \*

Each of my parents suffered and died from slow, unpleasant, increasingly debilitating (and incurable) illnesses. I suspect that given a choice, at least one of them might have chosen not to accept that route. But I would have respected any decision they made, because I believe that only the person who is dying has the right to make that decision.

Opponents of choice often cite the value of enduring suffering because it is part of God's plan for us.

Not everybody who lives in New Zealand believes in God, and I think it is just plain wrong for people who don't have religious beliefs to be bound by laws which are based on the presumption that we all believe in the same things.

It is not the government's job to favour one set of beliefs over another.

**J.K.**

\* \* \*

I have had to watch both of my parents and a sister slowly deteriorate until disease has taken them. It has been a very cruel and upsetting process to witness and I doubt that they would have

willingly gone through that process if they had had a choice. Watching a loved-one deteriorate and slowly succumb to either drugs or the disease is not a humane practice.

The long-lasting memory I have ingrained in my brain is the suffering they endured over weeks until their bodies were overtaken from disease. That is not humane or right. We treat sick and/or seriously injured animals with more regard and respect. We don't make them suffer. We kindly and compassionately make informed decisions to end their suffering.

**G.J.**

\* \* \*

I have now watched both my mother and mother-in-law pass away without dignity which was hard for them as ladies and for myself as a daughter/ daughter-in-law.

I have also owned two beautiful dogs. Both lived happy, fun-filled lives but at an old age became very dependent on family to be able to continue that life. In that case we were able to call the vet to our home and hold those dogs in our arms while they peacefully passed away.

Yes, there is a difference between the mothers and the dogs. The dogs didn't get to make their choice – that was made by caring family who did not wish to see them suffer.

The mothers both had to see out their miserable lives being totally dependent on family and rest home staff. Both mothers said if they could they would end their lives - if they had the ability - but would not implicate their families in their decision.

**J.H.**

\* \* \*

Three examples illustrate how it is difficult at times to ensure adequate abatement or alleviation of severe distress as a result of entrenched attitudes and lack of clear clinical guidelines.

Case A: An elderly diabetic was admitted to the rest home after an acute hospital admission when the presenting condition was semi-coma. The patient was over 90 and had refused all medication; there was a strong and definite wish to die. Alzheimer's Disease complicated the situation and there were several co morbidities, including gangrene of a limb. The clinical condition of the patient improved with the rest home care, but the gangrene also progressed. In a few weeks the situation was indeed grim, the affected limb was black but there was no physical pain (this is what may happen with gangrene).

However, the distress to both patient and the family was immense, it was an agony (to) witness progressive gangrene, the odour severe and the indignity and misery of witnessing the limb tissue flaking off affected all concerned - the patient, family and visitors and nursing staff.

The Hospice was consulted and the doctor attended. As the patient was morphine naïve (had not been on a significant dose of narcotic) a very small dose was prescribed, following present clinical guidelines. There was no concern for the psychological aspects of distress. I countermanded the advice and arranged far more complete doses of narcotics and other drugs

and the patient died peacefully several days later. I had sought another specialist opinion to support my prescribing, and it was necessary to speak firmly to nursing staff to follow orders, even though the pharmacology was going (to) greatly shorten life. It was a sad and anxious time for all.

Case B: An over 80-year-old patient, stable in another rest home, developed widespread abdominal peritonitis. This patient had developed a physiological bowel obstruction of three weeks' duration but this was not reported to the attending doctor. This likely contributed to the peritonitis although a clearance had been performed quite some time before.

It was clear the patient was going to die a painful, terrible death; there was no hope of successful treatment.

I prescribed medication subcutaneously to induce what was medically termed a "controlled coma". Some nursing staff were upset by this as they could not see the point of prescribing narcotics and other drugs for a patient who was not yet in severe pain.

The management were also unable to see that preventive measures to secure a good death were preferable to allowing the patient to suffer. The elderly husband strongly supported my care plan and she died peacefully, without pain, two days later.

Case C: This was one of the most shocking situations I have experienced and should never have occurred. The patient was a crippled elderly man who had been resident in the rest home for some time – he suffered from progressive muscular dystrophy, became unable to talk and confined to bed with major skeletal contracture deformities. I was asked to see him for a three-month review. He was in severe distress with terminal heart failure due to severe anaemia (haemoglobin level of 27, the lowest I have seen in a still living patient). This had not in any way been attended to by the rest home over the prior three months, even to provide relief of symptoms.

The poor man was alone in his room, gasping for breath, his eyes were pleading, agonised with distress. I requested immediate morphine in a dose to relieve distress and to call his relatives as he was dying. He did some hours later.

I made a complaint to the DHB as to the care of patients B and C and four others in that rest home. The complaint was fully investigated, and corrective measures were instituted.

**Dr Lannes Johnson, Mb ChB (Otago); FRNZCGP (Dist); MMed.Sc (Hons)  
Russell**

\* \* \*

Our daughter-in-law suffers from Huntington's disease. She now is in rapid decline with constant jerking of body, choking, falling, loss of speech, loss of mind, to name a few of the aspects of this horrific disease. She asked many times for the right to die. But there is no way around - it is simply forbidden by law to assist.

When I asked her why she didn't choose the option to step out herself she answered me: "Simply because I don't want to die alone." This is heart-wrenching.

**K.R.**



\* \* \*

I watched my maternal grandmother, my mother and her sister, my aunt, all die the most prolonged and inhumane deaths. They had each been confined to secure units at geriatric institutions for about five years.

‘Life’ inside one of these wards is a contradiction in terms. To spend days, months, years, locked away in pointless empty time, gazing into space, not being able to recognize one’s dearly-loved children and grandchildren.

Not able to read, write or converse, confusion stemming laughter. Lost independence, the ability to dress, nourish oneself or perform bodily functions in private. For those who have loved and lived creative lives of purpose and joy this is an unacceptable indignity.

I loved, cared for and honoured my mother for as long as possible before she had to go into full time care.



*Beryl Morton, Dale Lethbridge's mother.*

Given the high possibility I could be given the same diagnosis I have no wish to spend my last days in such a condition. I do not want my family to look into bewildered eyes as, frightened by strange faces and unfamiliar institutional surroundings, I eke out days, months, years.

**Dale Lethbridge  
Hamilton**

\* \* \*

As a nurse I was deeply affected by observing the final days/weeks of some people's lives when they were experiencing break-through pain which could not be alleviated by medication.

The desperation in their eyes and the pleading for the staff to end their suffering was hideous to see and the prolonged grief of their families who just wanted their loved one to be free was something no one should have to go through.

My dad died what some could describe as a peaceful death...peaceful for the staff maybe, but for me it was just awful. To see him sedated to the extent that he was unresponsive apart from dreadful moans as he became conscious enough to obviously feel pain so that more drug was administered was indescribably sad.

He was a man who was always in control and his helplessness in the face of his disease must have been devastating for him. Would he have taken the option of physician-assisted death had it been available only he would have known but I have a strong sense that he would have.

NONE of us have the right to decide what others might do when faced with imminent death. It is such a personal choice but no different to all the other choices we each make every day of our lives. I strongly support any changes in legislation which would allow ME to make MY CHOICE about the time and manner of my OWN death if faced with a condition which caused me unbearable suffering and loss of self.

**Louise O'Leary**  
**Morrinsville**

\* \* \*

My husband was diagnosed with Alzheimer's 14 years ago at the age of 63 and two days ago he turned 77. Almost five years ago he went into a dementia care unit. This was an awful time for him because of his very high level of anxiety and agitation.

This state led to him escaping a "secure unit" by jumping over a fence onto a yard of car wrecks and rubbish which resulted in a large head wound, a blood transfusion and a broken bone in his neck for which he needed six weeks of 24-hour surveillance so he wouldn't remove his neck brace.

For the last 2-½ years he has been in hospital care because he has lost all mobility. He can no longer stand up, walk, talk or change his position in bed. This is what he has endured for over two years. Over the last two months he has lost 6kg and now weighs less than 45kg. He has no flesh on his body. I can see clearly the very white colour and shape of the bones in his hand. His legs are skeletal and now he has stopped eating.

As I write this submission I am sitting in his room. He is going to die. He is going to die of kidney failure from lack of food and liquids because his mind is no longer able to send the message to swallow. How long is it going to take him to die? I don't know - a week or longer I'm told.

I consider he has been part of the "living dead" for 2 years. In that time I have seen patients who have never got out of bed, who cry out in anguish and I have seen other Alzheimer's patients in a tormented state before and when they are dying.

My husband is peaceful. But I don't know if he is pain free, because he can't tell me. I do know that I would be in pain if I was suffering some of his ailments: ongoing occurrences of thrush in his mouth and on his tongue, a skin cancer on his chest, broken and decayed teeth (which cannot be treated as he would have to be anaesthetised and he is too frail to undergo such

a procedure) and as he is a sufferer of Ankylosing Spondylitis and Ménière's Disease I can't help wondering if these are giving him pain. But he cannot tell me.

There is no hope for my husband and he is about to suffer a prolonged and tragic death. Why? I can't answer that because this inhumane way he is to die should not be allowed in our civilised society.

I understand that there are people with their religious views and moral values who disagree with euthanasia, and that is fine, no one is forcing them to adopt this. But they are forcing us to adopt their values and religious practices and I strongly object to this.

I know that my husband would have been a casualty of the Auckland Harbour Bridge if he had not already lost some of his mind when he was initially diagnosed with Alzheimer's. I know this because he had told me this all our life together. He was very clear that he would not want to live like this and I found this in writing in his personal effects quite recently.

I think that if you had visited him in this home on average 300 days a year for almost five years you, too, might have a strong view that letting people live like this if they don't want to is morally and ethically wrong. I know that I am going to take an Alzheimer's test in the very near future and I will commit suicide before I need to just so I don't have a fate like my husband's and other occupants of the hospital he is trapped in.

I will take my life earlier than necessary if I am diagnosed as likely to submit to Alzheimer's. Under such circumstances I would consider the lack of action on the matter of euthanasia by our legislators a crime against me because of the choice I would be forced to make.

I was once asked to assist with a family member's suicide. I suspect this happens to a lot of people and can I tell you, in case you've never experienced such a request, it is one of the worst things that you will ever experience. You are torn. You know that the suicide is legal but your assistance is illegal with hefty jail sentences attached. You know this person is going to suffer an agonising death as the body shuts down. You know that this person has always been there for you.

What would you do if your mother/father/sister/brother/husband/wife asked you to help?

Euthanasia should be legal to allow people to die with dignity and to allow their families to see them dying with dignity.

**S.J.**

\* \* \*

In 1994, my daughter at the age of 36 was administered aid to die with additional help from the doctors at the hospital.

We had watched this beautiful young mother suffer endlessly for many months, and could only agree when the request finally was made by the specialist to increase the drugs.

After watching ongoing suffering and loss of personal dignity, family members felt her leave us with much love surrounding her.

This should be the right of all people. We should not have to look for ways and means to take our own lives when the time comes.

**Fran O'Keefe-Jones**  
**Hamilton**

\* \* \*

In 1981, I sat with my mother in Auckland Hospital, as she died in extreme pain. Her doctors refused to give her more morphine, “in case it caused addiction”.

I believe she should have had that choice. On bad nights, I can still hear my mother's screams of pain. I do not want to die like that.

I believe that she would have been treated more compassionately in a modern Hospice, but that option was not available to her.

I have terminal, and untreatable, cancer. I am not afraid of death. We all have to die sometime. I do fear having a bad death.

I do not “desire to end my life”...I do want, if I am suffering intolerably, to have the right to say that I do not want to suffer any more. That is a very different thing.

I have great respect for the Hospice movement, and for the care they provide. I have confidence that I can expect to have good palliative care. But the reality is that death from cancer can be very painful. And even the best pain relief does not always work, for all people. I simply do not believe that there is any good reason why I should suffer unnecessary pain.

If I am not in too much pain, I want to stay alive as long as I can. But if and when the time comes that I feel that I am suffering too much, I would greatly prefer to be able to put an end to that suffering.

I know I can choose to refuse food and water, and thereby to die slowly of starvation and dehydration. But why should I have to starve myself to death, just because someone else has decided that, because of their beliefs, I must not be allowed to have my suffering ended?

**John Titchener  
Hamilton**

\* \* \*

I was with my father through his final illness. He was a gentleman, but he lost all self dignity, reduced to a wheelchair and wearing pads. He was not living, merely existing in horrible circumstances. He wished to die but we could not help him. It still haunts me.

**J.B.**

\* \* \*

My mother was terminally ill. My sister and I watched in great pain as she slowly got worse and worse. Our mother had a very clear and sharp mind. One night she took her own life and had to do it in secret.

**G.B.**

\* \* \*

I am a semi-retired GP/Counsellor/Supervisor and have for over 30 years cared for patients diagnosed with a life-threatening {so called terminal} illness. I also have been closely involved with the local hospice. During my medical training I was taught and believed that physical suffering could be prevented through the use of our ever expanding polypharmacy and medical palliative advances.

As a practising GP this belief turned out to be an illusion and was replaced by a reality with which I as a compassionate doctor have struggled with ever since.

I made a promise and committed myself to care for patients to the best of my ability to relieve their suffering, to have respect and honour their dignity, and to allow patients to have and make decisions about their illness, treatment, and general wellbeing. At times I failed in all three aspects.

There is evidence that around 15% of patients in Hospice care and programme experience unbearable pain and suffering and die. And this is in an environment where highly trained palliative care doctors and nurses work.

It does not need any statistical evidence that a patient's dignity is undoubtedly severely affected.

Patients can say "No" to treatment, to drugs, to certain procedures, to admission to hospice or hospital, but the most important and humane choice is for them to be able to say "No" to unbearable pain and suffering, and "No" to the loss of dignity when choice is withheld from them. Not surprisingly, the number of people resolving to take their own lives, while still able to do so, is increasing. I believe that we/patients have the right and deserve to be able to make that choice.

In this day and age all over the world, laws have been, or are being, changed to meet this need. There is overwhelming support for change. We can learn from already established models, sharing the same compassionate goal, to guide us in creating our own laws, based on compassion, knowledge and wisdom.

**Dr Hetty Rodenburg, MD, Bsc**  
**(Retired doctor, Lower Hutt)**

I have seen two people die from lung cancer, one being my mother at the age of 62 and a very dear friend at the age of 49. Hospices do a wonderful job and they say that there is no suffering.

I beg to differ - not only did they suffer a lot of pain - it was the mental suffering that was the greatest to these two people.

My friend Jo asked for it to all end and suffered for another two-and-a-half weeks before she was finally at peace. She had said all her goodbyes and was ready to leave this cruel disease behind. It was disgusting watching someone you love suffer in this way for so long. We don't let our beloved animals suffer. Why do we let people suffer?

**A.H.**

\* \* \*

As a New Zealand health professional currently working in a hospital setting (and previously involved with the care of palliative patients), I have found it heart-breaking at times to see the inhumane suffering endured by some of our population dying from terminal illnesses.

Sadly, I have witnessed many instances where palliative care is unable to provide the support and pain relief required to enable people to die in comfort and peace. This is the reality for many New Zealanders as they face death. They will have pain, they will lose their independence and dignity and they will struggle to breathe.

It can be ugly, no matter how good the New Zealand health system and modern medicine is. And it is not only the dying person who suffers - but also their families, their friends and sometimes the health professionals looking after them.

From a personal perspective I have watched two close family members die. Their deaths were not peaceful and their suffering will always remain as vivid painful memories in my mind.

Giving competent people with terminal illnesses the ability to make this decision with the guidance of medical staff will not only be of comfort to the person dying but also to people like myself who has witnessed the limitations of modern medicine and palliative care.

**P.I.**

\* \* \*

I have experienced first-hand the extreme distress - akin to torture - suffered by a family member in the weeks leading up to her death. She had decided that she was ready to die but there was no option available to her other than to refuse food and medication.

Had she been able to choose a medically-assisted death we would have been able to share her last days in the manner of her own choosing. Instead, we watched the excruciating and heartbreaking weeks of her slowly dying in pain and distress.

Denying people the choice of medically-assisted dying in cases such as this is cruel and has no place in a civilised and enlightened society.

**L.H.**

\* \* \*

I am a retired Registered Nurse. I have seen a number of people die. Many had easy deaths. Some died in appalling circumstances.

I particularly recall one patient, a middle-aged woman dying of breast cancer. The cancer had spread so that most of her chest wall was rotting. The smell was unbearably offensive, and no ventilation or air freshener could mask it.

Twice a day, dressings soaked in dead flesh and exudate would be removed, the hideous sight exposed to a nurse, often a stranger. The smell intensified and was very hard to tolerate without gagging. The patient sat, in an agony of mortification, as fresh dressings were applied. She was then left alone, in her stinking room, until it was time for the next dressing.

She was fully aware and alert, and not in pain. Her pain was easily and adequately controlled. She was waiting for her chest wall to rot right through, at which point she would die. Nothing more could be done to relieve her suffering.

I still have nightmares about it. If I found myself in a similar situation - and breast cancer is common in NZ - I would want assistance to relieve my suffering, by bringing about my speedy and peaceful death.

**Eleanor Schlee  
Hamilton**

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Over the last four years of her life my mother increasingly suffered from the impact of multi-infarct dementia (MID) - loss of brain function caused by a series of small strokes. A stroke (also called a brain infarct) occurs when the blood flow to any part of the brain is interrupted or blocked. Blood carries oxygen to the brain, and without oxygen, brain tissue quickly dies.

The impact of the disease made her very unhappy and depressed; she ended up utterly dependent on others for all aspects of her life support. Over this period she became a thin emaciated person with little presence or understanding.

The last few weeks were galling for us all, but especially my mother. All who knew her agreed that for her, her death when it came was a release and a blessing. It would have been more so had it happened a month earlier (as she clearly would have wished).

**Wyatt Creech  
Martinborough**

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I am now a retired nurse with 52 years of nursing experience. During the last five years of my career I worked in aged care and palliative care. During my life and while nursing I have been involved with the deaths of friends, family and patients.

A... factor influencing my views is the death of my friend's mother 12 years ago - a dynamic woman and loving mother aged 66. S. was a working as a registered nurse prior to her diagnosis of bowel cancer with secondaries. She was told she likely had 4-6 months to live.

She experienced such unremitting pain and loss of dignity during her short illness. Palliative chemo therapy was recommended and actively encouraged. Her last weeks of life were consumed with treatment and side effects of nausea, vomiting and unrelenting weariness. Her pain was always present - if well medicated she would be too groggy to be present for her family.

S. in the end would ask repeatedly: "Please help me die. I don't want to live like this." and "Please someone stop the pain. I can't stand this."

Following her weeks of suffering S. died in hospice. This was a very difficult and distressing death for her and for her family to witness. What S. wanted was to die at home surrounded by her family and to be at peace. What she got was distressing weeks of pain and suffering. Her release from this came at her death.

It is these experiences together with researching physician assisted dying (PAD) palliative sedation, assisted suicide and euthanasia that influence my views on dying and my own death.

I know that if I am stricken with a terminal illness and my suffering has become intolerable, despite palliative care interventions, I would like to have the ability to request help to die and be released from this suffering.

This choice does not seem to be an unreasonable request. Indeed it would seem more unreasonable to be left coping with intolerable suffering and tough it out till death finally comes.

In the palliative care setting there were also many patients who requested help to die. It is correct many patients are helped with support of the palliative care team, effective interventions and pain management. Their deaths were more peaceful.

However, not all suffering is relieved in palliative care and not all pain is or can be relieved. I nursed many patients who experienced intolerable physical and emotional suffering and those were in intolerable intractable pain.

For some patients, palliative sedation was initiated, at that time food and fluids were stopped. Death from their terminal illness or dehydration follows within hours or days.

Is this not a form of physician-assisted dying by another name?

Reported in the *NZ Herald* in August 2015 from a survey undertaken by P Malpas, K Mitchell and H Koschwanez in end-of-life decision making in general practice published in the *NZMJ* 24 July 2015 was the finding that General Practitioners are prescribing medication to patients knowing that this will likely hasten death.

Doctors therefore do this presently illegally and in a way that could result in a prison sentence and loss of their medical license. This practice has the potential to put both the patient and doctor at risk.

**Bets Blake** RGON, ADN, Dip PH  
**Kaukapakapa**

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My husband died in 2001 of oesophageal cancer diagnosed nine months earlier. He was given both chemotherapy and radium treatment, not to preserve and save his life but to try and lengthen his lifespan. Both these treatments in themselves are cruel to say the least, for a person's well being, but combined just to lengthen a life (unsuccessfully in this case) is even crueller.



However, what was even crueller was that his desire to end his life with what remained of any dignity he still had and no suffering went unheeded owing to the laws we have at present. He did not wish to have someone else suffer through prosecution because of his wants and needs which were against the law, so he carried on suffering further instead.

The pain management throughout was totally inadequate, causing much pain over the months of his illness from the illness itself, surgery and treatment he underwent, pain from constipation, and pain from loss of personal dignity due to being unable to do things like toileting and showering by himself.

Towards the end he was medicated to the point where he hallucinated, slipped into an almost comatose-like state and could no longer communicate his wants and needs properly. Despite all that, we could also still see that he suffered pain through his inability to end his life and he also had to watch his loved ones wait for his end and see their suffering.

Surely anyone with a heart would not allow an animal to suffer like we force our loved ones to suffer, so why do we do it? Treatment for terminal illnesses is not always adequate and even if it were, adequate is not good enough. The dying person's wishes should be paramount, like their wishes in their Will post death is. If their wishes post death are to be carried out by them writing a Will then their wishes prior to death should also be carried out. Why are their wishes post death more important than pre-death?

**P.S.**

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In April 2013 I witnessed the death of my best friend, aged 33, whom I had met and adored since my first day of primary school in 1985. C. suffered greatly in the days preceding her inevitable death. Her cancer caused excruciating nerve pain and the skin on her neck, face and right arm felt as though "someone was holding a hot iron on it".

A small team of close friends and family stayed at her side 24/7 and tried to comfort her while she was howling like an animal and screaming that she wanted to die.

Despite the fabulous team at Auckland Hospital's best efforts they were unable to control her pain and until she lapsed into a coma and passed 36 hours later. A peaceful passing this was not and three years later it still devastates me that C. had to endure that and her family had to witness her suffering.

The manner in which she suffered for those days had a significant effect on my grief for my beautiful friend. I could accept her illness, I could accept her death but I could not accept how much pain she endured and how powerless anyone was to control or alleviate her agony and distress.

**S.S.**

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My mother was diagnosed with breast cancer in 1973 and died in 1985. I stopped work to care for her six months prior to her death. Her slow lingering death was awful to watch. She was an articulate, intelligent, active woman and was always seeking new knowledge.

As the disease affected her brain she became unable to see properly – she could no longer read. She researched a drug she had been given to make her “more comfortable” only to discover it had the potential to reduce the size of the tumours in her brain and consequently prolong her death.

She was annoyed that the medical team, who were well aware of her opinion regarding prolongation of life when in the final stages of a disease, had duped her. She consequently discontinued the treatment. Watching her fade to a non-communicating, immobile, skeletal shell was very painful.

She had stashed some pills that had been prescribed to my father (who had suffered a heart attack) and when I found these I asked why she hadn’t taken them. Her reply being that she wasn’t sure she had enough “to do the job”. She and I had the opportunity to discuss life and regrets – one being the lack of grandchildren and another was not being allowed to choose when she would die. On reflection, if she had been given the opportunity to make the decision I think it would have been three months prior to the disease “killing” her.

**Jan Gilby** (who elaborated on her submission for this book)  
**Hamilton**

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I have had to watch, helplessly, family members and close friends suffer for many months (12+) before finally being released. My father used to beg me to get veterinary euthanasia drugs to “put me to sleep, I don't want this pain any longer”.

The medical people involved were still apologizing to me a couple of years after his death because they could do nothing to help him out of his pain and misery.

The Cruelty to Animals Act dictates imprisonment and/or very large monetary penalties for people who stand by and watch an animal suffer: the pain or distress to the animal is so great that it is necessary to destroy the animal in order to end its suffering.

It does not matter who or what caused this suffering - an animal can and is euthanised to prevent its ongoing pain and misery. Someone makes that choice for them -- we are asking to make that choice ourselves.

**J.D.N.**

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My elderly mother finally passed away on 23rd January after some 10 years of fighting multiple cancers. She was in palliative care for the last two years of her life, having made the informed choice not to pursue further treatments, as these were clearly not improving her quality of life.

Before Christmas, she told me she had had enough and wanted her life to end. She said she had suffered enough and no longer enjoyed anything anymore.

On January 10th, she suffered from a stroke which left her unable to eat, drink or talk. In her frail state, we thought the end would be swift and free her from her long suffering, but no. She lived another two weeks without any food or drink. When asked if she was ready to die, she consistently signalled that she was and wished the end to come. Yet, as we watched her deteriorate day after day, death cruelly left her waiting.

People who say "old folks decide when they leave" clearly have not witnessed the terrible hopelessness of someone who wishes to die but can't. My mother would not have chosen two weeks of dehydration and starvation if she had had a choice. She would not have chosen the burning sensation of morphine entering her arm every two hours. She would not have chosen her mouth drying out and her skin wrinkling up.

None of this was dignified. None of this was necessary. I wished she had had a choice. I wish I will have a choice if I find myself in a similar situation.

**L.D.**

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As the daughter of two parents who are in residential care with end stage dementia I feel strongly that all people should have the right to make choices regarding their end of life, at a time when they are able to do so.

In their increasingly rare and more lucid moments both my parents regularly state that they wish they could die. It is truly horrendous to watch two beautiful people who were highly intelligent, articulate and dignified lose all of their former selves and become angry, aggressive, fearful and totally dependent on caregivers to meet their needs.

They would never have chosen to be the way they are if they had been able, when they were of sound mind, to make decisions about circumstances where they would chose to end their lives.

My dog had a dignified death in old age because she no longer had control of her legs or her bowels or her bladder. My mother who was also a nurse, and spent most of her life caring for others, has to endure the indignity of faecal and urinary incontinence, of not being able to feed herself and of being swung in a hoist from a wheelchair or a commode into bed.

She spends most of the day crying and in a state of extreme agitation.

**Louise Forsyth  
Wellington**

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I had to watch my mother linger through months of zero quality of life with the full horror of Alzheimer's, wanting to end her misery but knowing that she would not want me in jail as the law stands.

As a proud woman, what indignities she had to bear and for what? I still wish I had had the guts to end her suffering!

Everybody who knew her agreed it was a travesty of human justice to treat a person worse than an animal. Every individual should have the right to die as they wish.

As far as safeguards go, a suitable panel of doctors, lawyers and family would make the decision. I can see areas having specialists for this part of the procedure. When this is integrated into our life-structure we will wonder why it wasn't done years ago!

**George Marshall**  
**Whanganui**

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My 41-year-old sister-in-law died in 2001 of lung and other cancers. Her last two weeks in hospital was a terrible experience for her and her family. Her parents, fiancé, 15-year-old daughter, brothers, sister and myself witnessed her suffering during that time.

Every day, her daughter visited and always spoke to nursing staff asking for help for her mother. I personally witnessed her crying while begging a doctor to put her mother out of her misery. From that day on, the doctors did not come to the ward between 4.30pm and 6.30pm as they knew the daughter would be there.

Virginia's suffering, despite the best efforts to reduce pain by doctors and nursing staff, was a shattering experience for all who visited her.

**Don Sandford**  
**Hamilton**

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Some few years ago, I cared for a terminally ill brother. He died aged 33. The day he finally took his last breath was at the end of a journey which had seen him suffer horrendously.

Did he take medication? Yes...Were there terrible side affects to this? Yes...Did he look at me like a wounded animal on countless occasions? Yes...Was there food in the house to feed him? Yes. Was he constantly vomiting? Yes. Was he in constant pain? Yes.

Could I lift a 6ft 4in man from his soiled bed because he was skeletel? Yes. Did he have the beginnings of an extended stomach due to malnutrition caused by vomiting all the time? Yes. Did his beautiful head of hair fall out all over his pillow? Yes. Did he need assistance for his ablutions and to be dressed? Yes. Was his mind and intellect functioning? YES! Did he know he was dying? Yes. Did he know he had no say when and how? Yes! Did he resent this? YES!

He was constantly mortified, and under more stress and anxiety because he had to have his family caring and attending to all the above.

To have placed him in other care, with strangers, was not an option, it caused him more distress. We attempted and it lasted one week. He needed to be cared for by those who loved

him. He detested being cared for by those who loved him. He was dying. He knew he was dying. We talked about his dying. He talked about euthanasia and was in full support of people having the right to choose when their life became as his had.

Ethically and morally, it ought to have been his right to choose a legalised medically-assisted death.

**N.E.**

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My mother suffered from emphysema. She had smoked since the age of 18 – heavily in the past 30 years, and had tried to stop numerous times but to no avail. Aged 84, mother spent her last four days of life sitting in a chair beside her hospital bed (she had been unable to lie down for many months,) in an induced morphine-coma from which she would quite often display signs of anxiety and restlessness.

According to the machines, mother's heart was strong but her lungs' function was virtually non-existent. We had been advised that mother would not have any decent quality of life after an event such as she had gone through.

I believe that mother would have welcomed the option/choice to make her farewells to her friends and family, knowing that her death would come swiftly, with her family and a physician by her side, rather than sit up for four undignified days, displaying signs of distress and anxiety. I do not think mother was in any physical pain, but her mental suffering was overwhelmingly evident. I could not watch her die in this way. Some of our family took it in turns to sit with her, and I know just how upset they felt. I definitely do not want to die this way myself.

Mother and I had talked often about how empowering it would be to have a legal choice in the manner of our dying if we were enduring intolerable mental and/or physical suffering with no hope of a dignified and quality future.

We had been following the Voluntary Euthanasia/End-of-Life Choice overseas debates, events, examples and legislations with much interest. Not so long ago, mother expressed a strong interest in the Swiss-based Dignitas, but she said she would not be able to afford the travel. Oh that we could have given her the death she wanted!

**Jan Randle  
Inglewood**

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I am deeply of the opinion that, with the proper controls and legal frameworks in place, physician-assisted euthanasia should be made available as an individual and legal right for any person suffering from a terminal and/or incapacitating illness.

I have come to this view after considerable time spent with my father who died of mesothelioma in 1991 and my eldest sister who died of breast cancer in 2007, as they underwent

hospice-based palliative care. In the last couple of weeks of their lives both expressed the wish to hasten their deaths and both, although given wonderful care by hospice workers, had to endure the pain, discomfort and prolonged agony of 'natural' deaths.

I have heard it said many times that with good palliative care, there is no pain and suffering for the patient - but the reality is that there most certainly is.

**A.C.**