

# Euthanasia & End-of-life Care Reader



## Introduction

Hurihia to aroaro ki te ra tukuna to atarangi kia taka ki muri i a koe.

Turn your face to the sun and the shadows fall behind you.

Welcome to this 'Reader' on euthanasia and end-of-life care. This compilation of medical papers, audio interviews, video-links, newspaper articles, lectures and submissions to parliament is intended to aid the reader's understanding and appreciation of complex theological, ethical and legal issues. There is a considerable amount of tension held in this small collection. Argument and counter argument are explored as you encounter the wide spectrum of beliefs held and defended.

A team from the Diocese of Waikato and Taranaki has assembled these resources at the request of its clergy. Although it is in part a response to the Hon David Seymour's End-of-life Choice Bill it goes well beyond that catalyst. The Team has attempted to collate resources that will practically help pastoral caregivers as they journey alongside those who are dying and their whānau.

We are indebted to the work and experience of the following who generously gave their time and expertise to help determine which resources would be most useful.

*Rev Julian Perkins has worked as an Ecumenical Chaplain at Waikato Hospital for the past two years. Prior to this he was long-term Chaplain to Sheffield Teaching Hospital (UK) and previously a Vicar in the Church of England.*

*Rev Juliet Drage has worked extensively in mental health and chaplaincy services, is a nurse, and was deaconed in 2001. Juliet champions the ministry of deacons and the plight of those living with mental health issues.*

*Heather Major is the lay minister in charge of All Saints' Community Church in St Andrew's/Bryant Park. She has a long history of Christian leadership, is a strong advocate of people living with disabilities, and journeyed with her husband throughout his terminal illness.*

*Rev Andrew McKean: Andrew is the current Ecumenical Chaplain at Waikato University and a Third Order member of the Franciscans. He is passionate about theological education and fostering inter-faith relations.*

*Rev Canon Sue Pickering: Sue has studied and tutored Biomedical Ethics and has had 30+ years of practical experience in pastoral and spiritual care, most recently as a chaplain in aged care where the complex issues around dying and death filled countless conversations.*

This reader is divided into broad subject areas as follows:

- Terms and Legislation: a short video; an overview of the terms associated with euthanasia and end-of-life care; some clarification around what Hon David Seymour intended by sponsoring the End-of-Life-Choice Bill.
- Care of Dying and Palliative Care: a series of lectures on death, dying and funerals; assorted approaches to spiritual care provided to those who are dying; suffering from a medical perspective.

- Theology and Ethics: a miscellany of theological rationales and secular perspectives.
- International Voice: submissions made to our Select Committee from a Dutch medical practitioner, and a journalist; a short article considering some international aspects of euthanasia.
- The Stories: video-links and select committee submissions from people experiencing end-of-life care or living/working those in a palliative condition.

There is no specific priority given to the order of items within each chapter. Nevertheless, we have tried to make it as logical and representative as possible. We also encourage you to watch Archbishop Philip's address on the topic of euthanasia and to share it with your communities (<https://www.youtube.com/watch?v=YxXpHMB4feM&t=15s>).

We trust that you will read the material in the spirit in which it has been prepared for you: prayerfully.

Compassionate God,  
 Beaten and hung upon the cross;  
 You know pain and suffering,  
 You know the value of human life.  
 Help us to comfort all those in distress,  
 To advocate for the vulnerable,  
 To honour both life and death.  
 Guide us as we care for one another,  
 And find our way back to You.  
 This we pray through Jesus Christ our Liberator,  
 who is alive and reigns with you,  
 in the unity of the Holy Spirit,  
 one God, now and forever.  
 Amen.

Ven Stephen Black  
 April, 2019

*We are very grateful to the many contributors represented in this reader. This compilation is for private use only. It has been provided to you free of charge and may not be re-distributed in any format. Any errors or misrepresentations are accidental and the fault of the compiler.*

Cover Photograph: *Pilgrim Markers to Lindisfarne*, taken by Rev Can Sue Pickering

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# Part One: Terms and Legislation

## What is Euthanasia?

To see a short video that outlines what Euthanasia is (and is not):

<https://notoassistedsuicide.nz/say-no-to-the-seymour-bill/what-is-euthanasia-tag/>

## "In Sure and Certain Hope" : References and Definitions

The following is an extract from the General Synod of The Anglican Church of Canada resource called *In Sure and Certain Hope : Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying* (Faith, Worship and Ministry: Task Force on Physician Assisted Dying) pp. 25-283. The complete text is available free here: <https://www.anglican.ca/wp-content/uploads/In-Sure-and-Certain-Hope.pdf>. The Taskforce consisted of:

- The Reverend Canon Eric Beresford. (Diocese of Toronto) Theologian and Ethicist; Rector of St. Timothy's Anglican Church, Toronto; Past President, Atlantic School of Theology
- Ms. Louisa Blair, M.A. (Diocese of Quebec) Medical Researcher and Writer
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- Reverend Canon Douglas Graydon, M.Div., M.Ed. (Diocese of Toronto) Coordinator, Chaplaincy Services, Diocese of Toronto; Previously Spiritual Care provider, Casey House HIV/AIDS, and chaplain, Princess Margaret Cancer Care Palliative Care
- Dr. Juliet Guichon, SJD. (Diocese of Calgary) Assistant Professor in Community Health Sciences, Cumming School of Medicine, University of Calgary
- The Rev'd Dr. Ian Ritchie, PhD. (Diocese of Ontario) Adjunct Professor, Queen's University Theological College, in pastoral ministry with the dying since 2002.
- Dr. Janet Storch, RN, PhD. (Partner from the Evangelical Lutheran Church in Canada) Professor Emeritus of Nursing, School of Nursing, University of Victoria

**ABANDONMENT:** In health care, the act of leaving a patient in need of care without care, i.e. walking away from that person which could be due to several factors, but is considered an unprofessional and inhumane act.

**ADVANCE CARE PLANNING:** An ongoing process of reflection, communication and documentation of a person's values and wishes for future health and personal care in the event that they become incapable of consenting to or refusing treatment or other care. Conversations to inform health care providers, family and friends—and especially a substitute decision-maker—should be regularly reviewed and updated. Such conversations often clarify the wishes for future care and options at the end of life. Attention must also be paid to provincial/ territorial legal and health guidance. (Canadian Nurses Association (CNA, 2015).

**ASSISTED SUICIDE:** The "intentionally killing oneself with the assistance of another who deliberately provides the knowledge, means or both" (Dickens et al. 2008, p.72).

**AUTONOMY:** Our capacity to be the authors of our own actions, to make free choices, and thus take up our role as co-creators with God

**BEST INTERESTS:** A term used to describe the basis for a decision made on behalf of an incapable person in the absence of knowing what that person would have wanted.

**BRAIN DEATH:** The term relates to the clinical criteria developed to determine that death had occurred in patients on life support systems that masked the occurrence of death, diagnosed according to the more traditional heart-lung

criteria. According to this definition, death has occurred when the entire brain, including the brain stem, have irreversibly ceased to function

**COMPASSION/COMPASSIONATE:** The ability to convey in speech and body language the hope and intent to relieve the suffering of another. Compassion must co-exist with competence. (CNA Code of Ethics 2008, p. 23).

**DEHUMANIZATION/DEPERSONALIZATION:** These are terms used in *Care in Dying* but not defined. One definition is “the perception of people as objects; the instrumental use and exploitation of patients and providers; coldness and indifference in social interaction; the repression and limitation of human freedom (loss of options) and social ostracism and alienation” (Howard et al. p. 12).

**DESIRE FOR HASTENED DEATH (DHD):** A term inevitably intertwined with physician assisted death (PAD) and physician assisted suicide (PAS) and euthanasia. (Branigan, 2015, p.1)

**DESIRE TO DIE STATEMENT (DTDS):** A patient’s expression of a desire to die, described as ‘death talk’ or ‘suicide talk’. Not all ‘desire to die’ statements represent suicidal ideation. They may have other foundations “not necessarily associated with a specific desire to expedite the dying process”. (Hudson, Schofield, Kelly, Hudson, Street, et al. 2006).

**DOUBLE-EFFECT:** A principle that means that “some human actions have both a beneficial and harmful result, e.g. some pain treatment for the terminally ill person might carry a possibility of shortening life, even though it is given to relieve pain and is not intended to kill the person. (Catholic Health Alliance, p.115)

**EUTHANASIA:** occurs when a physician intervenes directly to bring about the death of the patient, e.g. to inject a patient with a lethal dose of morphine at the patient’s request would constitute euthanasia.

Types of Euthanasia:

*Voluntary:* and act carried out according to the wishes of an informed and competent patient who without coercion requests that his or her life be ended involuntarily—occurs when a person who is competent to consent but, has not requested euthanasia, is killed

*Non-voluntary euthanasia:* refers to a situation in which the patient does not have the capacity to consent either through age or immaturity, unconsciousness, mental illness, or incompetence is killed.

**EXTRAORDINARY TREATMENT:** A treatment that is both ineffective and unduly burdensome; may prolong the process of dying rather than save life. (The use of these two terms above is discouraged by current experts in palliative care and by some theologians)

**PALLIATIVE CARE:** Care given to improve quality of life for people facing challenges associated with chronic, life-threatening illnesses. Through the prevention and relief of suffering, palliative care promotes early identification and comprehensive assessment and treatment of pain and other challenges, including physical, psychosocial and spiritual issues (CHCPA, 2014, p.2). Palliative care is provided in all care settings including homes, communities, institutions (e.g. hospitals, hospices, long term care facilities). It is care that starts at a diagnosis of a chronic, life-threatening condition, carries through until death and continues into bereavement and care of the body (Carstairs, 2010).

**PALLIATIVE CARE APPROACH:** Takes the principle of palliative care (dignity, hope, comfort, quality of life, and relief of suffering) and applies them to the care of people with chronic, life-limiting disease conditions by meeting their full range of physical, psychosocial and spiritual needs at all stages of life, not just the end. It does not link the provision of care too closely with prognosis but more broadly focuses on conversation with people about their needs and wishes. (Stajduhar, 2011).

**PALLIATIVE CARE IN HOSPICE:** Specialized end of life care that “aims to relieve suffering and improve the quality of life and death. It is “provided by health professionals and volunteers who give medical, psychosocial and spiritual support. The goal of care is to help people who are dying and their families to have as much peace, comfort, and dignity as possible. The caregivers try to minimize suffering as well as control pain and other symptoms so a patient can remain alert and comfortable as the person wishes. Hospice palliative programs also provide services to support a patient’s family. (WPCA & WHO, 2014, p.6). As of 2015, only 30% of the population of Canada has access to Hospice Palliative Care.

**PALLIATIVE SEDATION:** The use of sedative medications to sedate, either lightly or deeply, a person who is experiencing intractable symptoms such as shortness of breath, confusion or pain when all regular methods have failed or are not possible (Catholic Health Alliance of Canada, 2012, p. 127)

**PASSIVE EUTHANASIA:** Occurs where the intention is to allow the patient to die from a treatable condition. The example given is a decision not to treat a Down’s patient for duodenal atresia which is easily correctable.

**PHYSICIAN ASSISTED SUICIDE (PAS):** The provision by a physician of the means by which a patient ends his or her life, or the provision of information which a patient may use to obtain effective means to end his or her own life.

**PHYSICIAN ASSISTED DYING (PAD):** Where a physician intentionally participates in the death of a patient by directly administering the substance or by providing the means whereby a patient can self-administer a substance leading to his or her death (Canadian Medical Association, 2014).

**SANCTITY OF LIFE:** That human life is valuable and precious since human persons are made in the image and likeness of God.

**SUBSTITUTE DECISION-MAKER:** A capable person with the legal authority to make health-care treatment decisions on behalf of an incapable person. Since provincial and territorial legislation is not uniform across Canada, each jurisdiction has its own guidelines related to substitute decision-making and instructional directives for treatment and care. (CNA 2015, p.9)

**SUFFERING:** A state of real or perceived distress (i.e. physical or emotional pain) that occurs when a person’s quality of life is threatened. It may be accompanied by a real or perceived lack of options for coping, which create anxiety. (CNA, 2015)

**TERMINAL SEDATION:** Sedation provided to those patients where suffering is deemed uncontrollable. It is a means of keeping a patient asleep and pain free until they pass peacefully (Wilke, 2013). This would be equivalent to palliative sedation to unconsciousness.



**TERMINATION OF TREATMENT:** Refers to medical situations where medical treatment is no longer indicated and all treatment except **palliation** (food, hydration, pain relief, etc.) is withdrawn. *Care in Dying* included a lengthy summary distinguishing the law of refusal of treatment, intention, and passive euthanasia which is considered not helpful in this definition.

**VOLUNTARY REFUSAL OF FOOD AND FLUID (VRFF):** Choice made by an individual to refuse food or fluid voluntarily with our without the aid of physicians (Branigan, 2015).

**WISH TO DIE (WTD):** A patient's expression of a wish to die which must be understood because a superficial understanding could lead to someone taking the statement at face value or medicalizing it. (Ohnsorge, Gudat & Sutter, 2014).

**WITHDRAWAL OF TREATMENT:** Allows for the removal of therapies that are useless or unduly burdensome.

**WITHHOLDING, WITHDRAWING, AND REFUSAL OF TREATMENT:** Actions such as withholding or withdrawal of life-sustaining treatment (**WWLST**), such as ventilation, cardiopulmonary resuscitation, chemotherapy, dialysis, antibiotics, and artificially provided nutrition and hydration, is ethically acceptable. WWLST is allowing the patient to die from their underlying medical condition and does not involve an action to end the patient's life (American Association of Nurses, Position Statement on Euthanasia, Assisted Suicide and Aid in Dying, 2013, p. 5).

## Sponsor's Report on the End of Life Choice Bill: David Seymour

On 12 December 2018, the Hon David Seymour made his *Sponsor's Report* available. This report was accompanied by:

- a short video of introduction (<https://www.facebook.com/davidseymourACT/videos/eolc-sponsors-report/1064401427073290/>), and;
- a link to the report itself (<https://www.scribd.com/document/395592722/End-Of-Life-Choice-Sponsor-s-Report>)

This was a response to the 35000 submissions made to the Select Committee which sought to clarify the bill from his perspective. He recommended:

- the Bill should go to a referendum so the people decide;
- we put in provisions to strengthen palliative care;
- that we make it absolutely clear that this Bill is only for people who are terminally ill.

## End of Life Choice Bill: Eligibility Criteria

### **Age of the Person**

The End of Life Choice Bill limits access to medically assisted dying to people aged 18 years or over. This is to ensure that only adults who are capable of making this type of decision will have access to an assisted dying procedure. This Bill will not permit medically assisted dying to be practised on anybody under 18 years of age.

### **Citizenship or Residency**

The End of Life Choice Bill limits access to medically assisted dying to citizens or permanent residents of New Zealand. This Bill will not permit foreign nationals travelling to New Zealand to access medically assisted dying.

### **Terminal or Grievous and Irremediable**

The End of Life Choice Bill limits access to medically assisted dying to those who suffer from serious illnesses from which they will never recover.

If they suffer from a terminal illness, they must have a prognosis that shows six months or less to live. If they have a degenerative condition that is not terminal, it must be unable to be treated successfully, and 'grievous' - that is, a very severe illness.

This Bill will not permit medically assisted dying to be practised on healthy people, or those who can recover from their illness with treatment.

### **Advanced State of Irreversible Decline**

The End of Life Choice Bill limits access to medically assisted dying to those who experience significant loss of capability as a result of their illness. That means they have lost the ability to live a full life, such as by a combination of loss of mobility, loss of senses, and loss of ability to eat, drink or speak.

### **Unbearable Suffering**

The End of Life Choice Bill limits access to medically assisted dying to those who experience unbearable suffering that cannot be relieved in a tolerable way. That means, for example, that they experience extreme pain which cannot be adequately controlled through painkilling medication.

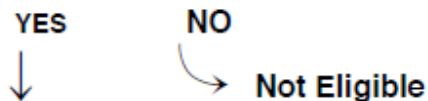
### **Ability to Understand**

The End of Life Choice Bill limits access to medically assisted dying to those who are able to understand the nature of assisted dying, and the consequence it will have. That means they are capable of giving fully informed consent to the procedure.

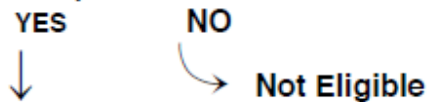
This Bill will not allow those without 'sound mind' to access assisted dying. That means people with significant learning disabilities, or serious psychiatric illnesses will not be eligible.

# Who is eligible under the End of Life Choice Bill?

1. Is the person 18 years of age or over?

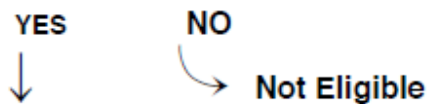


2. Is the person a New Zealand citizen or permanent resident?



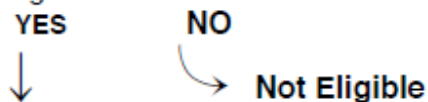
3. Does the person suffer from either:

A terminal illness that is likely to end their life within six months.  
OR  
A grievous and irremediable medical condition.



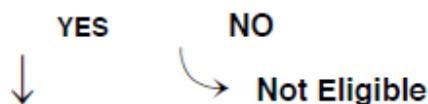
4. Is the person in an advanced state of irreversible decline in capability?

This means that illness has caused significant loss of ability to live a full life, that cannot be regained through treatment.



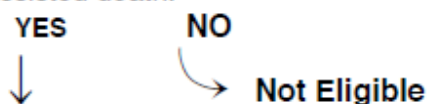
5. Does the person experience unbearable suffering that cannot be relieved in a tolerable way?

This means that the person's pain or suffering cannot be adequately alleviated through treatment that is available.



6. Does the person have the ability to understand the nature of assisted dying, and the consequences of it?

This means that the person has the capacity to give fully-informed consent to the procedure of an assisted death.



**If YES at every step - this person would be eligible to make a request under the End of Life Choice Bill**

# End of Life Choice Bill

## Process & Safeguards:

### Fully Informed Consent

The End of Life Choice Bill requires that the person's doctor fully informs the person requesting an assisted death of the details of their condition, their prognosis, and their other options for care at the end of their life. The doctor must ensure that the person has had the chance to speak to family, friends and counsellors about their decision.

The doctor must also check, to the best of their ability, that the person is making their decision to request an assisted death freely, without any pressure from any other person.

### Assessment by Two Doctors

The End of Life Choice Bill requires that a person's eligibility (meeting every criteria outlined overleaf) is assessed by two doctors. The first doctor must be the person's attending medical practitioner.

The second must be an independent doctor appointed by the SCENZ Group (a public body that will be created to oversee assisted dying). Both doctors must agree that the person meets all of the eligibility requirements.

### Assessment by a Specialist

If either one of the doctors is unsure that the person is competent (able to understand the nature and consequences of assisted dying), then a specialist must assess the person's competence.

This specialist must be a psychologist or psychiatrist, and will also be appointed by the SCENZ Group to conduct this assessment.

### Change of Mind

The End of Life Choice Bill requires that the person is able to change their mind at any time from the time of the first request for assisted dying. This is up to and including the time that the medication is provided to the person.

### Accountability & Reporting

The End of Life Choice Bill requires the Director-General of Health to create a body called the SCENZ Group (Support and Consultation for End-of-life in New Zealand).

The group's functions are: to make and maintain lists of medical practitioners, specialists, and pharmacists who are willing to act in relation to assisted dying (and provide these where necessary); to prepare standards of care; to advise on medical and legal procedures, and; to provide practical assistance if it is requested.

The SCENZ Group will appoint a Review Committee consisting a medical ethicist, and two medical practitioners, one of whom practises in the area of end of life care. The Review Committee must consider reports of every procedure carried out. The Review Committee will report its satisfaction or otherwise to the Registrar.

A registrar will be appointed to make and maintain a register of all prescribed forms held, all reports, and all recommendations made by the Review Committee. The Registrar must make annual reports to the Minister of Health. They must also establish a procedure to deal with any complaints about breaches of assisted dying law.

### The Prescribed Forms

The End of Life Choice Bill requires forms to be completed at every step of the process. These will be in standard form and require comprehensive information on actions taken. They will be kept on record by the Registrar so that accurate reports can be made on requests for assisted dying, and assisted deaths carried out.

## What is the process of the **End of Life Choice Bill**?

**1. A person tells their attending doctor that they wish to have the option of assisted dying.**

**2. The doctor must take all of the following steps:**

Advise the person of the prognosis for their condition.

Advise the person of the irreversible nature of assisted dying.

Advise the person of the impacts of assisted dying.

Talk with the person about their wish, at appropriate intervals.

Ensure the person understands their options for end of life care.

Ensure the person knows that they can change their mind at any time.

Encourage the person to talk about their wish with others, such as friends, family and counsellors.

Ensure that the person knows that they are not obligated to speak to anyone, but ensure that they have had the opportunity to.

Ensure that the wish has been expressed free from pressure by any other person, by speaking with other health practitioners and with members of the person's family.

**The doctor must record their actions that fulfilled the requirements above, and include these in the first part of a prescribed form.**

**3. The person must sign and date the second part of the form, with the doctor present.**

If the person is unable to write they are able to request another person to sign and date the form on their behalf. This must be done in the presence of the person, with certain conditions met.

**4. The doctor must decide whether the person is eligible for assisted dying.**

The criteria explained on page 2 must all be met.

**5. A second, independent, doctor must also decide whether the person is eligible for assisted dying.**

**6. If one or both of the doctors requests it, a third assessment of the person's competence must be made by a specialist psychiatrist or psychologist.**

**If both doctors (and the specialist, if requested) agree that the person is eligible, assisted dying can proceed.**

**7. The doctor must tell the person that they are eligible for assisted dying, and discuss with them both the progress of their illness, and the timing of the assisted dying.**

The doctor must make provisional arrangements to be available to administer the assisted dying medication.

**8. The medication can be prescribed and administered by the doctor.**

48 hours prior, the doctor must prescribe a lethal dose of a chosen medication. The person can choose the method of receiving the medication.

**The doctor must ask the person if they wish to receive the medication, and if so, provide it so the person can end their life.**

**Every assisted death under this law will be recorded in detail, and reported to a Review Committee.**

# Care Alliance Report on End of Life Choice Bill submissions to the Justice Select Committee

Report prepared on behalf of the Care Alliance by

Emeritus Professor Peter Thirkell

## Introduction

This report provides an analysis of 38,707 written submissions made to the Justice Select Committee on the End of Life Choice (EOLC) Bill, each of which was read by volunteers of the Care Alliance.

The overall impression when reading these submissions is that they represent the views and stories of a large, diverse and thoughtful cross-section of all New Zealanders; young and old (aged 8–94), different ethnicities (Maori, New Zealand European, Pasifika, Asian), different occupations and walks of life, religious and non-religious, conceptual and experiential. In short, the submissions paint a heart-felt and deeply human picture of the views held by many New Zealanders who have considered the implications of legalising euthanasia and assisted suicide, and had sufficient strength of feeling to write in and make their views known.

Most submitters wrote as individuals in their own right. There were 1,979 submissions from doctors, nurses and others involved with the health care sector, and 133 submissions from a variety of organisations with a strong interest in the Bill.

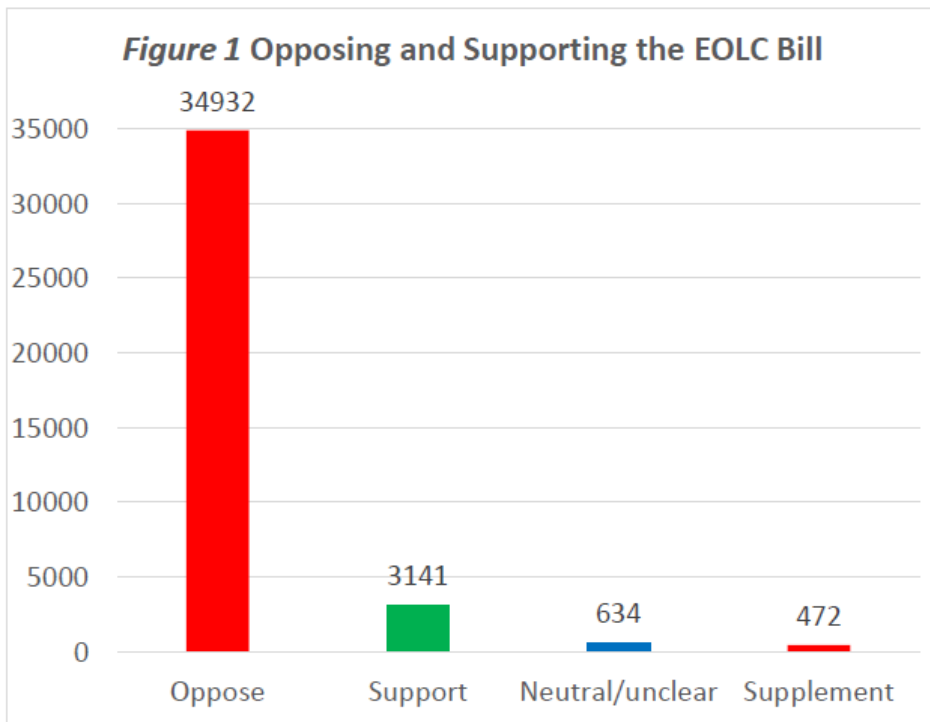
This report summarises the views, opinions and concerns presented by all of the submitters, along with some sub-groups of particular interest. It provides an overview of the main themes, insights and areas of concern to emerge, along with a description of key points and illustrative snippets drawn directly from the underlying submissions.

At the outset we would like to acknowledge each of the more than 38,000 ordinary New Zealanders who took the time and effort to share their insights, experiences, deeply personal stories, hopes and fears about these life and death issues.

## Overview of findings

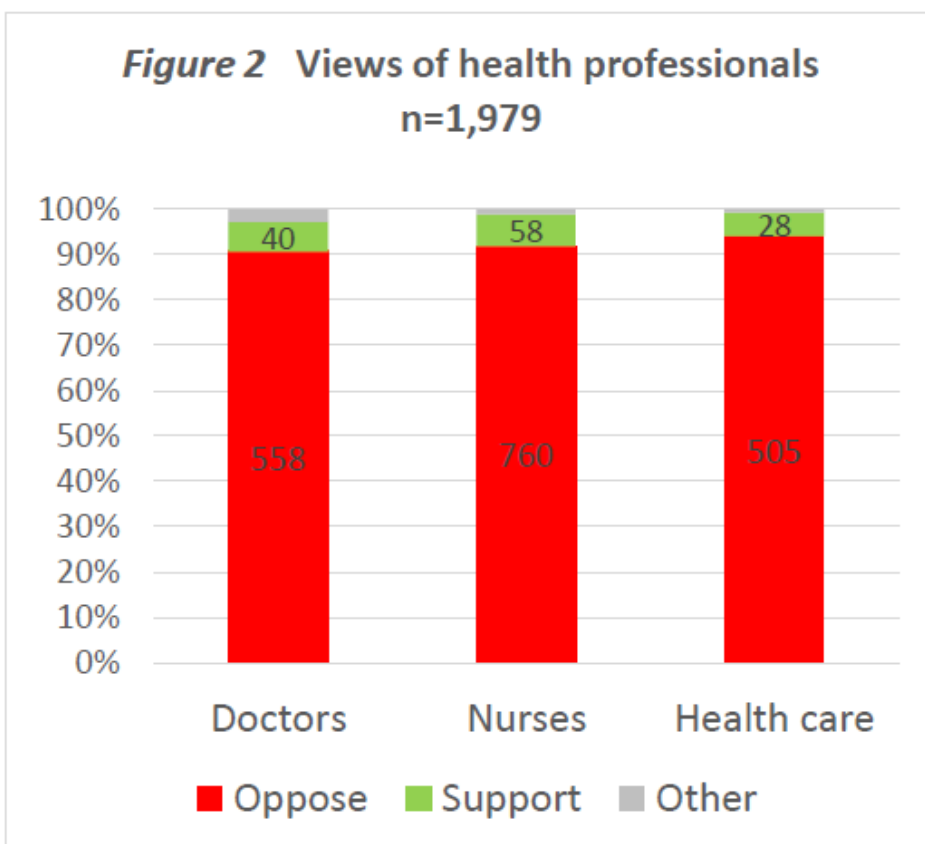
A substantial majority of submissions made to the Justice Select Committee oppose the legalisation of euthanasia and assisted suicide, and call for MPs to not pass the End of Life Choice Bill in any form. Of all 38,073 submitters expressing a position, 91.8% were opposed to the Bill.

Many submissions talked about the inadequacies of various provisions in the EOLC Bill, but in the end most people concluded that the adverse societal impacts of allowing doctors to end the lives of patients in some circumstances far outweigh any benefit that is argued. These concerns were found to apply both to the broader eligibility criterion of “grievous and irremediable,” and to the more restrictive “terminal illness” criterion proposed. This is because the ripple effects of euthanasia and assisted suicide spread throughout the society beyond the individuals immediately affected and irrespective of the eligibility criteria used.



Doctors, nurses and other health care staff

An overwhelming majority (93.5%) of submissions received from doctors, nurses and other health care staff who expressed a position were opposed to legalising euthanasia and assisted suicide as required under the EOLC Bill.



This finding is significant because the EOLC Bill imposes a specific moral duty on medical practitioners (i.e. doctors) to administer lethal drugs in response to patient wishes. While some

provision is made in the EOLC Bill for conscientious objection by doctors, many submitters identified a range of adverse follow-on consequences and contradictions in managing end of life care both for health practitioners directly, and for institutions providing palliative and end of life care. Hospices, for example, would be forced to participate in the practice of euthanasia and assisted suicide, despite this being diametrically opposed to their philosophy of holistic care, which is to neither prolong nor hasten death. These and other consequential effects are addressed more fully below.

### Other interested groups

Out of 133 submissions made by organisations, 96 took a position on the EOLC Bill and 90.6% were opposed to euthanasia and assisted suicide. Of the more than twenty organisations representing the medical, aged care and palliative care sectors, not one argued in support of legalising euthanasia and assisted suicide.

All 131 submissions made on behalf of New Zealand churches (100%) were opposed to the Bill, observing that the protection of human life is a fundamental cornerstone of society, and that true compassion means to stand with and hold each other in times of adversity, rather than placing vulnerable people at risk. These submissions were from across all of the mainstream Christian denominations in New Zealand.

There was a submission from a Muslim charitable organisation supported by 13 other Muslim welfare groups and organisations within New Zealand, emphasising that Muslims will never contemplate committing suicide or requesting any form of compassionate killing in a community where the values of duties of care, maintenance, compassion and kindness are a priority.

There was also a submission from a Buddhist group opposed to the Bill.

There were many submissions from people engaged in some way with the disability sector who focused on how disabled people would be impacted by the EOLC Bill. These were overwhelmingly opposed to euthanasia and assisted suicide because of the adverse impacts that it would have on disabled people, irrespective of the scope and specifics of how the Bill in practice might be implemented.

### Length and form of submissions

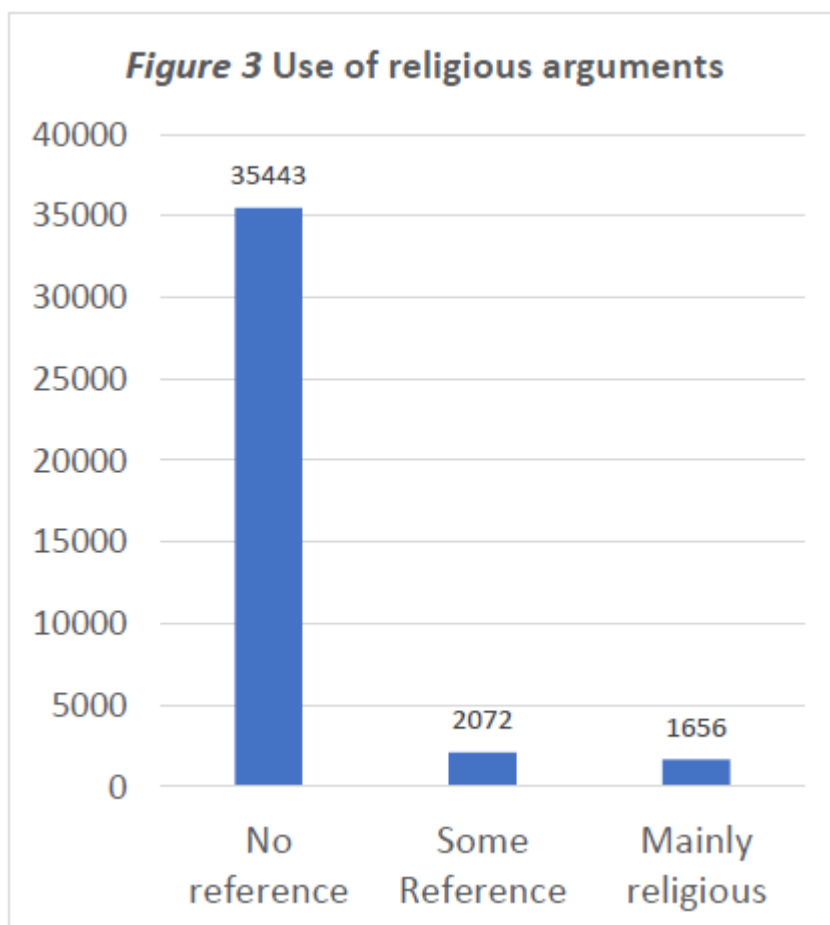
The average submission was about 250 words in length, and 53,435 pages of submissions were received in total. Most of the 3,141 people supporting the Bill made their submissions electronically. The 34,932 people opposed to the Bill were equally likely to either submit electronically, or in handwritten form which was subsequently scanned and converted to a pdf. This reflects a much broader-based constituency of people opposed to the Bill compared to those in favour.

There were very few instances of pre-prepared or “form” submissions on either side. By and large, everybody who wrote to the Justice Select Committee provided a unique submission outlining their own particular views, convictions, opinions and, for the overwhelming majority, deep-seated concerns about the End of Life Choice Bill.

### Religious arguments

Each submission was assessed for the extent to which, if at all, it made use of religious arguments against euthanasia and assisted suicide. While having personal religious views did not and should not exclude anyone from presenting to the Select Committee, it is useful to know the extent to which written submissions relied specifically upon religious arguments.





In the event, it was found that 90.5% of submissions made no reference at all to religious arguments.<sup>1</sup> Further analysis revealed that religious arguments sat in a largely independent category of thought represented by 5–10% of submitters. There was no systematic connection between their points of view and the broader range of perspectives and concerns represented across the majority of submissions. A small number of submitters in support of the EOLC Bill also made use of religious arguments.

### Content analysis of submissions

Distilling down and summarising the views of almost 39,000 submitters on a Bill as complex as the EOLC Bill is challenging given the breadth and intertwined nature of the issues, its far-reaching societal impacts, the overturning of long-established medical and health care ethics and codes of practice, and the gravity of a wrongful death.

To assist in this process, a content analysis was carried out on submissions using notes made during the analysis of each submission, aided by a text analytics tool. This allowed the generation of a themes map (appendix 1) highlighting the main insights, perspectives and concerns which emerged from the submissions – and how they are related to each other.

The central argument made by submitters in support of the EOLC Bill was for people to be granted access to lethal drugs administered by a doctor, on compassionate grounds, to relieve pain and suffering in response to a terminal illness, or other irremediable condition. In some instances, they

<sup>1</sup> In appendix 1 it can be seen that the “God” theme emerged largely independent of other themes. This means that a small minority brought a religious perspective to their submission, but the large majority relied on a set of arguments and concerns independent of religious thinking.

added the opinion that ‘dignity in dying’ could, in some circumstances, only be achieved by such means.

Some talked about palliative care, either to argue that euthanasia and assisted suicide can co-exist with palliative care as “just another treatment option,” or to argue that palliative care cannot provide the desired relief in all cases. It is noteworthy at this point that none of the organisations involved in the delivery of palliative care agreed with the notion that the two can co-exist, highlighting rather that they are diametrically opposed.

A number of submissions made in support argued that giving people the option of ending their own lives, when in the person’s own opinion there was no other means of relieving their suffering, should be legal as is the case in several other jurisdictions overseas.

The arguments advanced by submitters opposed to the EOLC Bill were more wide-ranging, with a focus upon the broader societal and health sector impacts of legalising euthanasia and assisted suicide. They fell into six main categories:

1. Implementing the Bill would lead to multiple adverse societal impacts on vulnerable people including the terminally ill.
2. Experience in the few overseas jurisdictions that have legalised assisted suicide and euthanasia is not reassuring, and it inevitably leads to broadened eligibility criteria.
3. State-approval through legalisation sends a powerful message that assisted suicide and euthanasia are socially acceptable, undermining suicide prevention efforts.
4. Ending patient lives is not a part of healthcare, medical treatment or what doctors are trained to do, and it will erode doctor-patient relationships and trust.
5. Terminating a life through administering lethal drugs is contrary to a medical ethics tradition that can be traced back to the Hippocratic Oath in Greek times.
6. Palliative care properly implemented and resourced adequately relieves suffering and demonstrates true compassion without loss of hope.

The following sections expand upon these six categories which were consistently raised in many submissions, along with illustrative quotes directly from the underlying submissions.

### Theme 1: Adverse impacts on vulnerable people and society overall

A majority of people opposed to the EOLC Bill made various references to what its effect on people in New Zealand would be, with around one third anticipating some form of negative societal impact in the event that the Bill was passed. Others expressed the conviction that vulnerable people across New Zealand would be badly affected one way and another. Specific groups identified as being placed at risk by this Bill included:

1. Elderly people (with mentions of elder abuse and fear of being a burden specifically)
2. People with mental health issues
3. People suffering from depression
4. Disabled people

Broadly speaking, the concerns related to the generalised adverse social signalling that would follow from allowing doctors to administer lethal drugs to end peoples’ lives, and the genuine risk of wrongful deaths as a result of undetected coercion.

## Illustrative quotes from submissions

Individual submission [para 3]: “I am also concerned at the effects this law change would have on the way society thinks about caring for people. There is a major social justice issue at stake here, in protecting the vulnerable. Our country invests huge amounts of time and money (as it should do!) protecting the vulnerable in our society - the sick, elderly, mentally ill, young people (including millions of dollars spent trying to prevent youth suicide). Why would society suddenly turn the tables and allow the legalised killing of certain members of society? Especially when there is such an enormous scope for potential abuse? Vulnerable people may feel they are a burden on relatives or the tax-paid health system, and very easily, with state-sanctioned killing, a 'right' to die could become a 'duty' to die.” Link 541

Registered Nurse [para 2]: “Where I work, I have seen people who are suffering and cannot see the light at the end of the tunnel, and who have told me they wish they could die, however I have also seen these same people recover and gain a new lease of life. These are people who would be so vulnerable to this Bill or its future inevitable expansions.” Link 946

### Elderly people

Practicing Geriatrician [para 3.1]: “In my practice as a geriatrician I frequently see cases of people entering residential care, or making health decisions, not because this is their preferred decision, but because it is ‘best for the family’. It is important for the committee to note that elder abuse is a) common in society b) frequently unreported and c) most often perpetrated by those closest to the individual. As such these familial reasons quoted for desire of hastened death are highly open to pressure and coercion, which is unlikely to be documented ...” Link 1156

Individual submission [para 2]: “Supporters of the Bill insist it is creating a choice. No one is going to be forced to commit suicide and the Bill protects against such pressure. This statement is disingenuous. Vulnerable people will feel pressured to commit suicide, and of course they will feel pressured into signing documents attesting to the fact that they are making this choice freely of their own accord. Humans are like that ... We want to leave some inheritance to our children rather than seeing it all go in medical and hospital costs. Innocent people who do not wish to die will die as a result of this Bill. It is impossible to safeguard against people lying about their motivation.” Link 1264 7

### People with mental health issues

Palliative Care Nurses [para 36]: “... there are significant implications for young people in the context of an already growing mental health crisis and high adolescent suicide rate (Brazier, 2017 [page 22]). A law that allows access to assisted dying for people of 18 years places other young people in our society at significant risk. Legislation supporting assisted dying has been associated with an increased rate of total suicides and no decrease in non-assisted suicides (Jones & Paton, 2015). We acknowledge and support the draft MOH, NZ Suicide Prevention Action Plan, and consider that a law supporting assisted dying would critically undermine suicide prevention strategies.” Link 1956

General Practitioner [para 1]: “As a doctor I have had the privilege of caring for people in immense suffering and seeing people of all ages and identities struggle with physical pain and mental illness. I have seen patients recover from places of immense suffering to enjoy and achieve great things. I have also seen young New Zealanders with so much future potential take their own lives and have lifted a 20-something year old girl up by her legs to take the weight off the noose that was holding her blue head. I find it astonishing that our country is considering legalising euthanasia and to me it is a very scary and sad prospect.” Link 973

## People with depression

Herbalist treating people with serious illnesses including neurological conditions and advanced cancer [para 6]: "... after the diagnosis of a serious chronic illness or after an accident that is likely to cause chronic disability, people often become temporarily depressed as they grieve the lost possibilities in their life that they may have had to relinquish due to illness or disability." Link 2098

Palliative care nurse [para 1]: "A depressed person does not know that their depression may pass and they will feel the joy of living again. They need hope, not an exit strategy." Link 57

Disability Rights Commissioner: [para 44] "The absence of a specific period to allow reflective consideration of options and choices is concerning. This is relevant in the context of both terminal and non-terminal conditions – both of which are known to give rise to periods of grief, despair and depression of varying intensity and duration. Quick or reactive decisions could be made in times of low mood ..." Link 1935

## Disabled people

Individual submitter [para 5]: "I oppose the Bill in principle because I believe in the moral value of life, and the moral dignity of every human being. I oppose the Bill in practice because it is vague, badly drafted, imprudent and flatly dangerous. I oppose the mentality behind the Bill as a disabled person whose life is equally valuable. And I oppose it as a citizen who wants to live in a country marked by solidarity, kindness and care, not killing. Link 2369

Individual submitter [para 11]: "As someone with a disability, I worry that others with disabilities will not be encouraged to see how full their life could be, and instead consider death as a preferred option. It also concerns me that there are financial incentives for governments, insurance providers, and health care providers to advocate this position. It is obviously cheaper for some disabled people to die than for them to be a lifelong burden to the healthcare system. I worry about myself that I may become further incapacitated in the future. Should I then think my life is not worth living? Should others encourage me to think of death as an option? Link 2367 8

## Theme 2: Overseas experience not reassuring

About one in ten people opposed to the EOLC Bill made reference to what has happened in countries where euthanasia and/or assisted suicide have been legalised. Many of these specifically identified the Netherlands and Belgium by name, in part because these are the euthanasia regimes closest to that proposed in the EOLC Bill. Three areas of concern in particular were raised by submitters. The first was the evident growth in deaths in the years following legalisation, well beyond the rate of growth in the overall death rate. In the Netherlands for example, there were 2,120 euthanasia deaths in 2007 which grew over a one decade period to 6,585 in 2017.

The second concern raised was that the criteria for eligibility are inevitably expanded over time, because once the door is opened to euthanasia and assisted suicide the arguments for an expanded regime shift from the relief of suffering to a rights-based argument for eligibility so as to avoid discrimination. Submitters opposed to the EOLC Bill made reference to, and in some instances provided evidence for, such a "slippery slope" phenomenon whereby eligibility criteria are increasingly liberalised over time.

The third concern raised in submissions echoes an earlier point about societal shift whereby euthanasia becomes increasingly normalised as the default option for those approaching the end of life, rather than an isolated last-ditch response in extreme circumstances. Many submitters expressed alarm at the seeming inevitability of such normalisation.

### Illustrative quotes from submissions

Individual [para 4]: “I do not think the reasons to promote this Bill have validity now and I think in future it will be even less valid as the taking of life would be so open to further exploitation. My reading of data from Holland and Canada indicate the ever increasing numbers of assisted deaths after their legislation allowing termination of life.” Link 27081

Individual submission [para 2]: “I come from the Netherlands where euthanasia is legal and I have seen the steady progress, in a remarkably short time, from the legalization of voluntary euthanasia with many safeguards to a situation where there have been cases of non-voluntary euthanasia forcefully administered, euthanasia administered for any and every reason where life is considered not sufficiently pleasant, comfortable or secure. There is increasing pressure on those who are aged, sick, impaired or dependent to choose euthanasia rather than be a financial or social burden.” Link 849

Dutch Professor and former Euthanasia Review Committee member [para 2]: “The fact that PAD is made legal, may have contributed to a gradual paradigm shift from PAD as a last resort to PAD as a default way to die. The fact that the quality of palliative care has become much better in the past 15 years has not prevented the numbers from going up. PAD is increasingly seen not as a last resort but as 'a good death after a trajectory of excellent palliative care' To illustrate: in some Dutch cities, such as Alkmaar and Almere, euthanasia now accounts for about 9% of the total mortality rate. Within these cities, there are postal code areas in which euthanasia accounts for up to 15% of deaths. The consequence may be that valuable knowledge in the field of palliative care will leak away. I conclude that the legalization of euthanasia is not only the end of discussions and not only the official recognition of hitherto unrevealed practice, but also creates new realities.” Link 25952

### Theme 3: Assisted suicide and euthanasia undermine suicide prevention efforts.

A dominant theme in submissions from those opposed to the Bill was concern that State approval of assisted dying sends a powerful message that assisted suicide and euthanasia are socially acceptable, thereby undermining suicide prevention efforts specifically, and the treatment of those who suffer from mental health illnesses more generally. Many people in the front line working with those who struggle with suicidal ideation, anxiety, depression, and mental health issues were deeply concerned about the impact of this Bill and its implicit endorsement that hope can be lost, and that some lives are simply not worth living. A number observed that this was exactly the opposite of what true compassion should be.

Some medical practitioners (including six oncologists) who submitted against the Bill observed that depression and despair are not uncommon reactions when patients are told that they have a terminal illness such as cancer. By working with patients through this initial sadness and despair however, many were able to enjoy months (and in some instances years) of life before finally dying of their illness. Some submitters told of working with young people who struggled with suicidal thoughts, or attempted suicide, but who with good support and loving care were able to come through and experience a better life. Other submitters told of the devastating impact that suicide can have on families and their wider social circles, and expressed the view that adverse impacts upon wider family and friends still occur even when it is an assisted suicide. Some were shocked that, under this Bill, a person could opt for assisted suicide without family or friends being told in advance.

### Illustrative quotes from submissions

General Practitioner South Auckland [para 5]: “I am concerned about the message sent to our youth about the validity of suicide - we are telling youth that suicide is not the answer and yet,

saying to our disabled and terminally ill that it is. Those youth that have talked to me about the issue have mentioned the double standard.” Link 1046

Individual submitters [bullet point 5]: “We question the purpose of such a Bill when it is clear that Government is concerned about so many people – especially young – committing suicide. It seems to us that Government appears to promote a double standard in looking into plans to prevent people from committing suicide yet, at the same time, enabling the law to permit euthanasia. On January 23 of this year, when announcing an inquiry into mental health the Prime Minister stated, “Our suicide rate is shameful.” How can we reconcile this with an attempt to introduce assisted suicide?” Link 11438

Registered Nurse [para 1]: “I have worked as a registered nurse for the past 40 years, majority of that time spent in Mental health, predominantly acute nursing and for the past 15 year as the sole community mental health nurse for \_\_\_ on the West coast. Over the many years I have nursed probably hundreds of people who have at some time “wished to die” usually in response to severe depression / anxiety or just the burdens of life as we know it. My experience is that most of these people have recovered and gone on to lead normal lives and often spoke of the terrible experience and the disbelief that they could have been so unwell as to think of taking their own lives or wishing that they could simply have the means ‘just to die’.” Link 12665 10

Individual submitter [para 3]: “I disagree with the agents of the State being involved in intentionally ending the lives of some of its citizens.” Link 7225

Registered Nurse [para 2]: “I am a registered nurse and so I do see a lot of suffering. In my particular place of work I have seen a lot of attempted suicides and while you do understand the patient's suffering that led up to their suicide attempt and feel your heart break for them, what breaks my heart even more is to see the hurt of the friends and family members of the patient. They are hurt that the person could find no support or hope in them ... They feel betrayed, angry, and sad. Suicide may have made the patient relieved of their suffering, but it creates a whole new kind of suffering for their loved ones. I feel that the assisted suicide bill would be no different in its effects.” Link 911

Dutch Professor and former Euthanasia Review Committee member [para 7]: “The claim is often made that if we want to prevent violent suicides, we should provide people a way out. The availability of PAD is said to be an alternative for patients who want to have a suicide. This may be true for some. But as for the Netherlands, despite the wide availability of PAD and despite the numbers rising from 1,800 to 6,091 in the period 2007-2016, the number of suicide cases went up by 40%. The rise was all the more significant since in exactly that same period we made assisted dying possible for the categories of people that do commit suicide. I see two reasons for the increase in suicides. First, PAD-procedures (especially for patients with a psychiatric condition) are bound to take weeks and months, which is way too long for a patient with an acute death wish. Second, the ever ongoing discussions and media attention for death as a solution to suffering may contribute to a cultural climate in which death is seen as a solution to any form of severe suffering. This mechanism (‘speaking about assisted dying leads to more death wishes’) was officially suggested by Spokesperson Jan Latten of the Dutch Bureau of Statistics (CBS) in June 2017, when he presented the latest suicide figures.” Link 25952

General Practitioner high needs area [para 9]: “[The EOLC Bill] is a massive shift in thinking to the current practice of dealing with a suicidal person. Currently when someone is suicidal I treat them with the aim of recovering from their suicidality and maintaining their safety. Instead, I will have to weigh up whether or not their desire for suicide is reasonable and meets the very broad criteria. The phrases "grievous and irremediable medical condition", "advanced state of irreversible decline

in capability" and "unbearable suffering" are very open to interpretation. If their request does meet the criteria, I will then have to actively assist them to die or lead them to someone else who will." Link 964

Individual submitter [para 1]: "I strongly oppose the End of Life Choice Bill. I work with high at-risk and behavioural teenage boys. My husband and I have cared for over 400 youth, over 16 years of working as Specialist Caregivers for MVCOT. We have dealt with youth suffering from severe depression, youth who self harm, and many youth who have lost a friend or family member to suicide. I personally lost my Mum to suicide 8 years ago. Hence we are all too aware of the suicide epidemic NZ has. I do strongly believe that by legalising euthanasia, we are sending the wrong message to our youth." Link 17075 11

#### Theme 4: Doctor patient relationship

As noted above, 615 medical doctors made submissions to the Select Committee. Of the 598 who had a clear position, 92.4% were opposed to the EOLC Bill. Their general view is that administering lethal drugs to end the lives of patients is contrary to all that doctors stand for and are trained to do. Many cited the position of the NZMA that "allowing death to occur is fundamentally different from a deliberate act that has the primary intent of terminating life. ... If doctors are authorised to purposefully terminate a person's life, or help terminate a person's life, however carefully circumscribed the situation, they acquire an additional role that is contrary to the nature of the doctor-patient relationship."

Apart from doctors themselves, many other submitters who were opposed to the EOLC Bill made reference to the role of doctors and their longstanding tradition of bringing healing where that remains a possibility, and relief of suffering to those facing life-threatening illnesses. Some made reference to the trust relationship between doctors and patients, and how this would be compromised by the EOLC Bill. The views and opinions of doctors are very influential for many people, and the present law allows for wide ranging discussions between patients and their doctors for care, treatment, symptom management and palliation – while stopping short of considering lethal drugs as "another treatment option." Changing the law to include this option would place a large burden on doctors, knowing the extent to which patients rely upon their advice and their sensitivity to even subtle nuances in the way that doctors respond to people enquiring about assisted dying.

#### Illustrative quotes from submissions

Individual submission [para 1]: "With respect to the medical community, our doctors are the very people who should protect, care and heal, and with whom we should have a relationship based on trust. ... Please do not ask those who train to care for us to participate in what they consider to be unethical. Leave them instead to focus on saving lives and providing real care to the dying." Link 7906

Pacific Child, Youth and Family Integrated Care Trust [para 1]: "We, as medical doctors and leaders in the Tongan and Pacific community in New Zealand, OPPOSE any and all efforts by the New Zealand Parliament to legalise euthanasia or medically-assisted suicide in the event of a terminal illness or an irreversible condition that makes life unbearable." Link 1957

Individual submission [para 2]: "Doctors already have a stressful job. This could add enormously to their stress. ... What a burden for a doctor to carry - knowing they informed someone they had a terminal illness and as a result they chose to end their life when perhaps the illness may not have been terminal after all. This could affect the way doctors diagnose patients, their relationship with the patient and the patient's family." Link 7530

General Practitioner [para 6]: “I am greatly concerned how the legalisation of euthanasia will impact doctors and other health professionals across the country. The great majority of New Zealand doctors are opposed to this bill, evidenced by the New Zealand Medical Association's position statement. The legalisation of euthanasia would disregard the opinion of a large, trusted, essential profession and require it to facilitate the very thing it is opposed to. ... None would be impacted as greatly as the palliative care and hospice services which are already understaffed and underfunded for the essential and excellent services they provide.” Link 973 12

General practitioner [para 6]: “I am concerned that this Bill fundamentally alters the relationship of doctor and patient from one of trust and power given by the patient to the doctor to strengthen, extend and improve that patient's health/life, to one where the power to end life becomes part of the package. I want to remain totally committed to the LIFE of my patients, not having to then work with them as they decide if they want me to refer them for termination of that life ... I work in a South Auckland low decile practice with mostly Maori, Pacifica and Indian patients. I have not encountered the desire to end life or this intense need for control and autonomy that was present in the previous white middle class practice that I worked in. There seems to be great faith that family can be trusted to be there for them in their dying days, that they will be well cared for.” Link 1046

Specialist palliative care doctor [final para]: “I believe that there are other ways to deal in compassion with suffering people. I do not believe that changing the Law of the Land is right or needful. On the other hand, it will change our society over the next generations, ethically, relationally, and in medical interactions. I don't believe this has been adequately considered by either the elected representatives who voted for the Bill or by the population as a whole who are afraid of death, the unknown that surrounds it, and do not understand the options already available to manage suffering.” Link 1487

Public Sector Doctor [para 4]: “this bill asks doctors to put aside their professional opinions and experience and act as handmaidens to others. Assisted dying is provided at the patient's request, regardless of what the doctor, in their professional opinion, thinks is best for the patient. There is no provision for doctors to discuss the benefits and risks of the proposed action and yet this would happen before any other proposed treatment.” Link 1160

Oncologist [para 2]: “I have been involved in the treatment of cancer patients since 1995 and have as one of my specialty areas, the treatment of patients with high grade, terminal brain cancer. This background has given me the enormous privilege of walking alongside patients and their families at a stressful, harrowing time in the lives and subsequently for many, being alongside them as they die. It is this background which I feel has fashioned my views such that I stand in opposition to “active euthanasia/ physician assisted suicide (PAS)” and wish to submit against Mr Seymour's bill.” Link 37347

Psychotherapist and Hospice Counsellor [page 2 para 3]: “If health providers do not have the resources to spend the time required to uncover the less conscious suffering of a person, decisions will be made in reaction to minimal superficial information resulting in poor treatment decisions. If decisions to euthanize are made under these circumstances people will die without the opportunity to work through their suffering or to change their mind.” Link 35070 13

### [Theme 5: The Bill breaches a long-standing societal and ethical understanding that doctors should not intentionally end a patient's life.](#)

A number of individual submitters, medical practitioners, and nurses made reference to the millennia-long understanding that a doctor should not administer any lethal substance or otherwise intentionally end the life of a patient. They noted that this ensures continued confidence and



absolute trust on the part of patients that medical practitioners and nurses will always act in their best interests, and in accordance with widely accepted bioethical principles. Many affirmed the position of the New Zealand Medical Association, the World Medical Association and other peak bodies in medicine and palliative care which have maintained a longstanding position that euthanasia and assisted suicide are unethical.

Many of the medical doctors who made a submission were concerned about the potential for parliament to impose on New Zealand society a practice that has historically and continues to be seen by the large majority of doctors as totally unethical. They also argued that the conscientious objection provision does nothing to ease the ethical contradiction.

### Illustrative quotes from submissions

Medical practitioner [page 3 bullet point 3]: “This bill puts the GP in a conflict between ethics and the law. The law will allow doctors to bring about a patient’s death while our professional bodies regard the practice as unethical.” Link 2230

General Practitioner [para 2]: “The act of taking somebody’s life through an active process is not a peaceful action. One of the cornerstones of medical ethics is non-maleficence, to do no harm, and it is difficult for me to reconcile this with the participation in the active taking of a patient’s life.” Link 37321

Individual submission [para 4]: “For doctors to deliberately end the lives of their patients is a contradiction and an affront to their professional ethics. There is no such thing as a right to ask another person to kill you.” Link 25815

Individual submission community care worker [para 1]: “I oppose the intent of the End of Life Choice Bill because I believe in the value of all life. I believe God made us and we do not get to decide when we are born or when we die ... I work as a carer in the community and see many people suffer with a variety of conditions. Their conditions do not make them any less valuable ...” Link 3468

Muslim charitable group [page 10 para 7]: “Islam provides ... an atmosphere in which the individual is morally, emotionally and physically supported, more especially by those who suffer ailments and terminal illness. Muslims will never contemplate committing suicide or request for any form of compassionate killing in a community where the values of duties of care, maintenance, compassion and kindness are a priority.” Link 13

General Practitioner [page 2 para 4]: “Whichever profession is called upon to execute the euthanasia process would severely damage its social trust ... It should be noted that current medical ethics place a responsibility to that ethic above the law of the land. The conflict would be a very negative one for the profession and for our society.” Link 26378

Registered nurse [para 3]: “I became a nurse to make a positive difference by caring for my patients with the goal of sustaining life, irrespective of the anticipated length of my patients lives. Those two principles, the ending or sustaining of life, are incompatible.” Link 396 14

### Theme 6: Palliative care works but needs proper resourcing

A large number of people opposed to the EOLC Bill made reference to aspects of palliative care within New Zealand, and the value of its holistic approach to care for those who need it. These include rapid advances in palliative medicine over recent years, the international standing of the New Zealand palliative care sector, and the emergence of palliative medicine as a specialist field within its own right. Palliative care is strongly linked to the work of hospices around New Zealand, which enjoys a remarkable and sustained level of goodwill and volunteer support from the public. A number of submissions noted that the Bill imposes euthanasia and assisted suicide upon the whole

hospice sector, as has happened elsewhere, despite this being contrary to the very essence and approach of hospice care.

Palliative medicine specialists and nurses, speaking from their personal professional experience, argued that no one needs to suffer unbearable pain under well-managed palliative care. There was recognition that the quality and consistency of palliative care services around the country is not yet to the required standard, particularly in rural areas. It was also argued, however, that investing in additional services and qualified palliative professionals to achieve the necessary quality of service is a far more compassionate and effective way to make progress than simply resorting to lethal drugs to end peoples' lives.

Many submitters opposed to the EOLC Bill made reference to the importance of family in walking with a loved one facing daunting circumstances such as a terminal illness. These comments were intertwined with numerous personal accounts of hospice care, and the loving supportive environment provided for the dying person as well as for family members.

### [Illustrative quotes from submissions](#)

Doctor [para 6]: "I strongly believe that if the public were educated about real palliative care and experience it to the highest standard then they will change their minds about wanting assisted suicide to occur. The public have unfortunately a very wrong and skewed view of palliation. This country needs to place more funding and training into palliation for ALL conditions where the patient has a life limiting disease, not just cancer." Link 1081

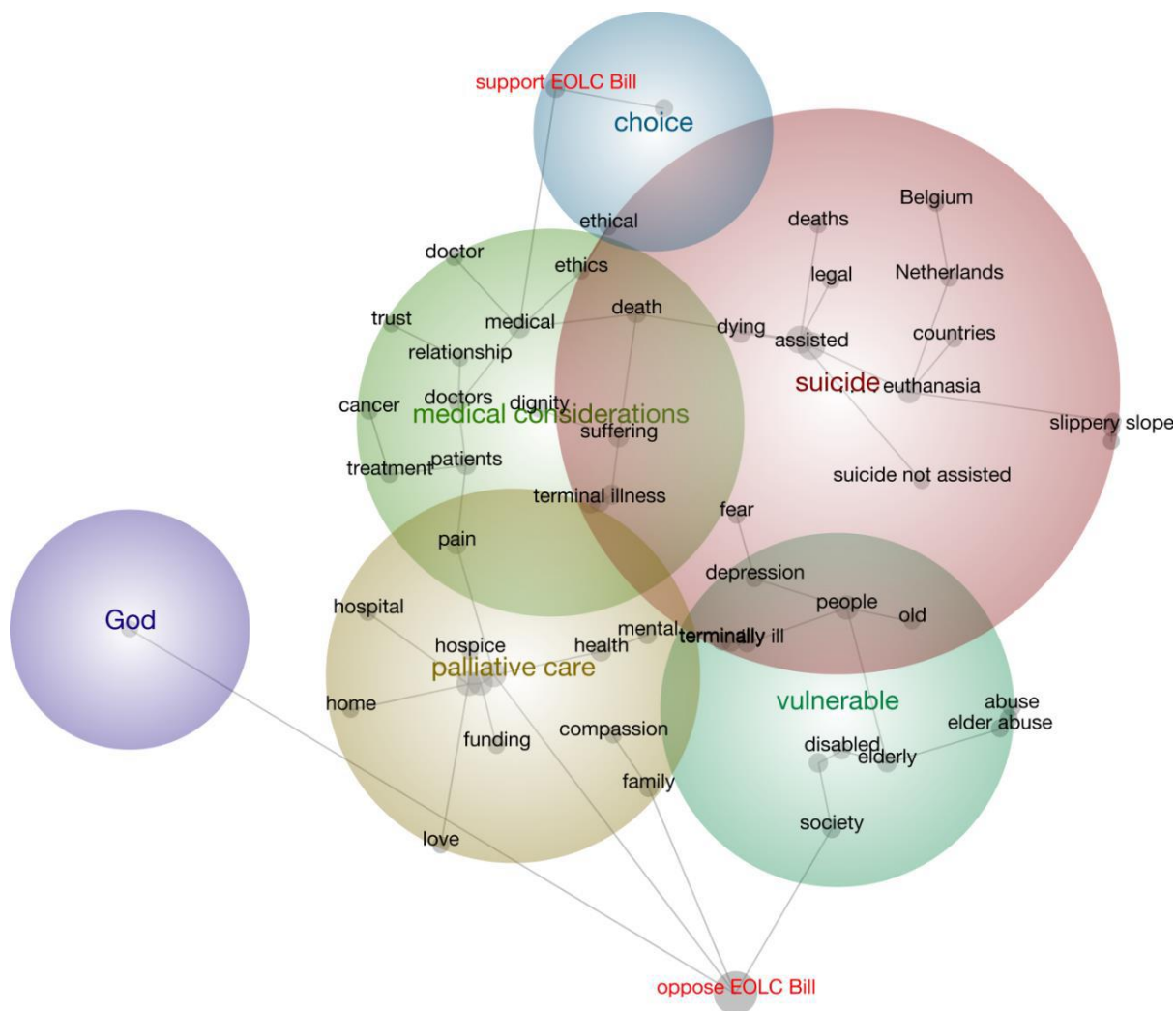
Individual submission [para 2]: "We had my mother-in-law come to stay with us when she knew she had just a few months to live. This bill would have short circuited those last few weeks, she didn't want to be a burden, but it was a time of great love for us all. Yes the whole family put ourselves out to have her there, but it was an enrichment, a deepening understanding of life, and i found it a privilege." Link 11801

Palliative medicine specialist [para 2]: "I believe that [the Bill] will impact adversely on hospices which currently can be seen as a place of 'safety' for patients. It will impact on my role as a palliative medicine specialist and possibly make the role unsustainable for me personally. I could not and will not refer a patient to medical colleagues for the purpose of facilitating euthanasia." Link 1128

Public Sector Doctor [para 1]: "... this bill approaches death with an individualistic lens. It fails to speak to the communities and whanau groups that an individual exists within. It extracts death and the individual and places them in a vacuum. Yet death affects those left behind. The way we as a society approach death affects our communities and our nation. Death should not be simply a matter of choice. We must hold it carefully, we must provide love and care to those who are dying, but we must not see it simply as a choice." Link 1160

### [Appendix 1 Summary of themes and insights emerging from the submissions analysis](#)

This diagram summarises the main themes and insights emerging from the content analysis. It is essentially a 'road-map' of the underlying ideas, arguments and areas of concern brought forward by submitters who both supported and opposed the EOLC Bill.



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1. The map shows the locus of ‘supporting’ and ‘opposing’ submissions relative to each theme. Those who support the EOLC Bill for example are more likely to talk about choice, suffering, and dignity for the individual. Those who oppose the EOLC Bill are more likely to talk about its impact on vulnerable people, palliative care, suicide, ethical and religious concerns, and relationships with medical practitioners.
2. Colours towards the red/orange/yellow end of the spectrum indicate more prominent themes, while those towards the blue/purple end indicate less prominent themes. Green indicates moderate prominence. The size of the circle has no significance other than reflecting the number of sub-concepts within each theme.

## Appendix 2 Technical note

Submissions were downloaded from the submissions and advice section of the New Zealand Parliamentary website as they became available until March 22<sup>nd</sup> 2019, using Bill reference 74307. They were sorted into batches for reading and analysis by Care Alliance volunteers. Each analyst was provided with instructions on how to read and extract the required information so as to ensure consistency of approach. The subsequent coding was checked and moderated by Professor Thirkell and combined into a unified dataset for analysis.

Submitters clearly in support of or against the EOLC Bill were recorded directly as ‘support’ or ‘oppose’ respectively. If a submitter made comments about aspects of the Bill without stating their

own overall position, they were recorded as 'neutral/unclear.' Similarly for submitters who were unclear about their overall position.

Where an uploaded submission provided supporting or supplementary material related to another submission, it was recorded as a 'supplement.' Where a covering letter had been uploaded separately from the main submission, this also was recorded as a 'supplement.' In some instances a person's main submission had an identifier appended by Parliamentary staff such as "Supp 1" or similar (389 instances). In this case the covering letter rather than the submission itself was coded as a supplement (192 instances).

Every effort was made to minimise double counting of submissions by this and other means, but it remains possible that a few submissions were double counted. To the extent that this did occur, it is unlikely to affect the proportions of those in support of and against the Bill.

Opposing, supporting and neutral/unclear submissions were included in the content analysis – but supplements were excluded.

There were ten instances where a listed submission could not be downloaded. These were coded as 'supplements' and excluded from further analysis.

Final tally to reconcile 39,179 submissions loaded on the JSC site as of March 22<sup>nd</sup> 2019:

Submissions opposed to EOLC Bill	34,932
Submissions supporting EOLC Bill	3,141
Submissions neutral or unclear about Bill	634
Supplements/covering letters/misc	472
TOTAL	<u>39,179</u>

# Part Two: Care of Dying

## Hamilton Winter Lecture Series 2018

### Introduction

In August 2018 the Hamilton City Ministry Group sponsored a winter lecture series on dying and living. They were in turn sponsored by DV Bryant Trust and WEL Energy Trust. This event marked more than 20 years of annual lectures.

We are most grateful to this body and all the speakers for their willingness to make these resources available to clergy and pastoral care ministers in the Diocese of Waikato and Taranaki.

### Ian Kilgour: What can we do to ensure a good death?

Let me commence with a question. What do you imagine is the single most important feeling we need to experience when approaching our death?

#### **A sense of completion fulfilment and peace !**

People of course have a range of feelings and anxieties, if not fears. Woody Allen facing this inevitable truth said of death, "***I'm not afraid of death, I just don't want to be there when it happens.***"

*Or the foreboding Shakespeare when he said, 'As the waves rush to the pebbled shore, so do our moments hasten to their end'*

Death can be approached with a sense of foreboding or it can be positively embraced, particularly if you have a deep sense of fulfilment about the life you're leaving. As Kipling put it "***If you can fill the unforgiving minute with 60 seconds worth of distance run, yours is the earth and everything that's in it'***

All too easily we **avoid** thinking about our death but **the premise of my book**, is that by thinking about it and preparing for it, fear or anxiety can be dispelled and the experience can be embraced as the next exciting part of our journey. We can die well!

#### **Now to the booklet .....**

What I've prepared in this little book is '***no pie in the sky when you die***' sort of stuff. Essentially it's about bringing one's life in this world, to a peaceful completion with deep sense of fulfilment, and this can be achieved by people of faith, little faith or no faith.

I wrote the booklet – because there is a dearth of material written for the person facing their death in contrast to the amount of material written for bereaved persons.

**The book is best described as a resource for chaplains** to use with people who may have been given a terminal diagnosis or who are in the latter times of their life yet with some months or even years to live. As they reflect on the contents of the book questions may surface which can open up discussion with the chaplain. Alternatively, family members can read sections of the book to their dying loved one as it contains many well-known verses & readings of comfort and hope. Some have said it has helped opening up discussion about a subject that is very personal and that can be awkward to raise. It couldn't be too weighty or complex but something easily pick up and dipped into.

**The first section** is about some practical advice for getting one's affairs in order. Last wishes, Advanced Care planning, One's Will and Enduring Power of Attorney, Funeral Arrangements. People

find that if these matters are in order they can relax more and have a tidy feeling about letting go. Small loose ends can trouble disproportionately.

The next part deals with 'remembering exercises' written in the first person singular, and **is about consciously reviewing one's life**. This I believe is of great practical value. I've been with a number of people who, approaching their death have said, "I've done so little with my life", or "I've wasted so much of my time", or "My life hasn't added up to much".

Every person has three things in common. Everyone's life is made up of **significant places, significant events and significant people**. (quote from book, page 9.)

Prompting such questions triggers memory and by recording what surfaces on the note pages provided or at least talking about these memories, one comes to realise that there's an awful amount of living on which to reflect and take heart from. You can start to trace how those significant places, events and people have shaped and challenged your life, giving substance to who you are.

It is instructive to acknowledge that the Māori way of facing the future is by looking at it through the past. If we do look back through our past, the good stuff and the hard stuff, then we'll see the real value of our life.

I deal briefly with coping with the hard stuff and use the illustration of the young artist seen collecting broken pieces of coloured glass from the shoreline of Holy Head Harbour in Ireland where the glass buoy's once used lie broken. An older man was curious and asked what he was doing. The young man invited him to his little log cabin and showed him a lovely stain-glassed window in the making. This is a marvellous parable of the redemptive possibilities implicit in life when we consciously gather up the broken pieces of our lives. Left broken on the shoreline of our life they would remain dangerous and useless, but in the hand of a craftsman can be worked in a new pattern of beauty. I personally believe the action of God's Spirit as the Master Crafter is always to this end. There is woven deep in life an evolutionary aspiration towards completion and wholeness.

Another very helpful approach is how we handle 'Divestment' of our material assets and personal treasures. **Doing this we can actually practise the art of dying**. Prof Joseph Campbell the famous mythologist argues that in the first half of our life we are necessarily acquisitive, accumulating property and things to provide for our life and family but in the second half of our life we should increasingly divest ourselves of all our physical and emotional dependencies, letting them fall away, so we can concentrate on the enduring values and our inner or 'sacred self'. We come into the world naked and that's the way we leave with the exception of who we are and what we've made of ourselves.

*Downsizing is often the accompaniment of the ageing process anyway so it can be gone about with meaning and satisfaction when it allows the essential 'you' to be found under all one's personas and accumulations.*

*Did you see the Seven Sharp item about the people who decorate their caskets! Now that's colourful preparation but a somewhat external effort. More important is the inner colour and quality of the 'sacred self'?*

**The second section** of the book is about spiritual understandings of death and dying and references a range of views.

Of necessity the book has been written in an inclusive way, remembering that chaplains serve people of all faiths and none. So evangelical Christians may be disappointed but there is no intention to pressure or convert but rather to respect and help each person cope with their own

personal journey, affirming their faith tradition and/or the values they have embraced throughout their lives.

***This preparation for one's death can be wonderfully meaningful and enriching, as we anticipate our cosmic journey. A bit like how intrepid adventurers felt as they set out to discover new worlds.***

**I love the story of the little girl who asked her mother where she came from to which her mother said, the Bible says we come from dust and we return to dust. Puzzled the little girl thought for a moment and said, 'Well under my bed there must be someone coming or going!'**

The truth is we know next to nothing about the world to come. In one sense death just appears to be death which happens to every species under the sun. **But the good news according to faith and science** is that our true selves, our spirit or immortal soul, call it what you will, does not die. All the elements which make up our being are re-absorbed back into the universal energy of life and never die. The Biblical record of Creation states we were made from the dust of the earth and science has now confirmed that it is 'stardust'. We are made of the elements and stuff of the universe! New discoveries in quantum physics indicate that we are all bundles of energy and are in relationship to everything else in creation, ever changing but never dying!

The **third section** is a collection of readings from various faith traditions, poetry, verse, hymns, prayers and benedictions that are pertinent and helpful.

*A florist arranged two bunches of flowers. One arrangement was for a funeral being held in the town and written on the card was, "Rest in Peace". The other bunch was for a friend relocating her shop and on that card she wrote 'enjoy your new location. Unfortunately they got delivered to the wrong addresses. The bunch that went to the funeral had the card reading' "**Enjoy your new location**'.*

Imagine yourself in the womb of your mother all those years ago. Before birth you had no inkling of what awaited you and likewise we have little idea of what awaits us beyond this life but nevertheless there are many pointers and intimations from a wide range of perceptive and spiritual sources. Of course they are expressions of hope and require trust to believe. The descriptions of how heaven will be in religious scriptures are just human constructs, attempts to describe what is not possible to know. Expressing ineffable concepts and hopes in human language.

Of course Jesus certainly attested to the survival of life after death but gave very little detail, perhaps because in his humanness he didn't know or if he did and shared too much of the detail, it would have reduced our grip on this life and our weakened our determination to tough out the hard stuff.

Whatever we believe about death, we all have an interest in death. Most dying people I've had to do with are not afraid to die but they are concerned about **how** they will die. Whether or not they'll cope and remain dignified. I believe everyone, of faith or no faith, can die well, although having a faith or deeply held values can be of real help.

**All great spiritual leaders throughout history, including Christ** have assumed the reality of life after death. But we need to leave behind the old creation story that describes death as a punishment from God for human sin and focus on the fact that all species are transient and on what Jesus said and did about death. He reframed our views about death forever. In this life we need to live fully and then we die so we can continue our spiritual development beyond this life in whatever form that is.

Jesus lived and taught that God's spirit is ever with us and before us. God's Spirit is the ever-present companion, a travelling presence, leading us into the next phase of life. In some of the most well-

known words of all time, ***"The Lord is my shepherd .....though I walk thru the valley of the shadow of death I will fear no evil, for you are beside me and your rod and staff comfort me"***.

We come from the creator God and we return to that same God. So, you are not on a journey **to** God, but rather on a journey **with** God. As Paul said, ***"We live and move and have our being in God"***.

This all joins with a deeply held inner conviction that there is something more, and that it is greater than we can ever imagine. As St Paul quotes from Isaiah, ***"Eye hath not seen, nor ear heard, neither has it entered into the heart of humankind, the things which God hath prepared for them that love him."***

As Gibrán says, *"Life is eternal, and love is immortal, and death is only a horizon; and a horizon is nothing save the limit of our sight"*.

***In summary, I believe that whatever we believe about 'life beyond death,' we should aim to wrap-up life on this planet in a positive way. And we can help any dying person to review and re-value their lives however hard it's been, so they can come to their end with a deep sense of completion and peace.***

### [Alistair McBride: Understanding the Grief Journey](#)

As we put the series together my colleagues on the committee felt that I had something to say about the journey with grief so here I am. This is a personal approach, but one which I have taken into my pastoral work and found those I sit with in grief or mourning find comfort and support.

Eric Bogle wrote a song about his father's death and his response to it. I want to share some of the verses with you through this presentation. Fittingly the song is titled "Journeys"

How clear the river runs  
Beneath the noonday sun,  
Through trees it twists and turns  
In light and shade.  
In the Summer's warm embrace  
Nature flaunts her bonny face;  
a more green and peaceful place  
God never made

How long is long?

This is a question that has cropped up over the forty years of my ministry as I have offered pastoral care to many, from those in the early path of grief, to those years on from the death of their loved one. It is a question that comes from a particular perspective, often unconsciously present, that I want to suggest pervades our western culture. While we talk about living in a post-modern world, much of our thinking is guided by a mechanistic, technological mind set. Everything that seems a problem has a solution. Any solution therefore has a process which if done properly has an end point. In our solution-based, time-limited way, we want to know how long something will last so we can move on to the next thing, and what we will look or be like after we've gone through the process – so we know we've arrived.

But is this the best way to approach grief?

I want to explore a couple of alternative images using examples from my pastoral work and from my own experience.

But first some definitions to explore.



These come from a paper called *Life after Death: A Practical Approach to Grief and Bereavement*.

*Grief*: The psychological, behavioural, social, and physical reactions to loss of someone or something that is closely tied to a person's identity.

I wonder about the notion of "reactions" here. There is no reference to an emotional response, nor a spiritual response

*Anticipatory grief*: A grief reaction that occurs in anticipation of an impending loss.

I experienced this 10 years before Denise died. It had a profound effect on our relationship at the time. It came not with the initial diagnosis, nor even through the chemo and surgery she went through, but after one of the oncologists consultations while Denise was still in hospital where they said "We know some of the cancer has escaped the area and we have no way of tracking where it has gone, but it is almost certain it will return." We talked and then I returned home and in the middle of preparing my evening meal I broke down with this enormous sense of loss. My world, the world we had built together was in the process of being deconstructed. And yet, at the same time I had to continue living, living with the one who was leaving one day.

*Bereavement*: The period after a loss during which grief is experienced and mourning occurs.

My question here is what happens to a person when the "symptoms" of grief occur outside of this period. It raises issues of when is bereavement over. If grief "reappears" then did we get the period wrong, the process wrong. I have some examples to mention in this regard.

*Mourning*: The process by which people adapt to loss.

Here I find as a minister helping people at the time of death that many of the time-honoured rituals that surround death often mirror the path we walk through our emotions. This is usually the time of the most intense emotions, and the emotions are reactions to the situation rather than any adaptation to it.

*Complicated mourning*: Delayed or incomplete adaptation to loss.

I want to come back to this because I think I have a different take on it which hinges on what we mean by complete adaptation to loss.

These definitions go along with what I observe as the increasing pathologisation and medicalisation of grief. Once it is seen as having a pathological component then it becomes a problem and, therefore needs to be fixed. The Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association in its 5th edition in 2013 removed any time exclusion for bereavement completely, whereas it had previously classed as a disorder from two months after a death. In other words any 'grief response' could immediately be classed as a major depressive disorder, and prescription drugs given to "cure" the bereaved person. I find in passing it is curious to note that the root words for psychiatrist are "soul physician", but they have determined to speak about "mental disorder" as the core of their work, whereas we the clergy have always had "the cure of the soul" as an integral part of our calling.

I don't know where the NZ medical profession stands on this, but for those of us involved over the centuries in journeying with those who have been bereaved, we think we might just know some different things about grief and mourning and their place in life.

I want to explore two ideas, and in between address some issues with the Kübler Ross Model.

The first comes out of my exploration of post-modern thinking. I have derived it from the idea that the language we use helps us construct the world of meaning we live in. We build the world we live in. That helps us interpret everything, the physical reality we experience, the emotional and psychological responses, and it constructs the meta-framework that helps our world cohere. Of

course we don't do this in isolation. It becomes a lifelong project which begins as soon as we start interpreting the language around us. As we grow up we first of all take on the world constructed by our parents and family, then the influences become wider as we experience first school, then friendship, and then moving into the adult world. Some of us then form partnerships with particular people, through marriage, living together, through civil unions. Here we share the task of constructing a world of meaning together. Our language is full of examples of how this works – The two shall become one; or “Therefore shall a man leave his father and his mother, and shall cleave unto his wife: and they shall be one flesh”. One of the consequences is that within that union, there develops a shared understanding of how the world we live in works. Of course I am over-simplifying and you can no doubt think of couples who seem to live in their own little worlds separate from the other, yet even they need to be able to communicate across that divide.

This world we build together we share with our children but, as we found for ourselves, so we find our children taking that and building on it, deconstructing some and constructing a new world, some of which we as parents may be able to share and some we may never really understand.

As time goes on, the strength or solidity of our jointly built world is tested, refined, strengthened, damaged, repaired, but it is our world that we inhabit, within the wider world of our society and interacting with the worlds of others. We have constructed the reality in which we live.

One of the pieces I use in funeral services from time to time goes like this:

“Death is an ending! It is a loss of everything! Death, though it comes to every one of us, is a tragedy of major proportions.”

And at times of death we need some grounded actions that acknowledge the reality we are now living in. That is the place where funerals and funeral rites become important. Often they mirror the emotional and spiritual journey we take as we mourn and grieve, doing things which anchor our loss, but also free us to move on.

Eric Bogle again.

*On the river bank I stand,  
My father's ashes in my hand;  
I'm there at his command,  
One promise left to keep;  
Though in my mind the past appears  
A sad parade of wasted years,  
Grief and guilt both fuel the tears;  
At last I weep,*

Using this reality construction model, life can be pictured as a series of interlocking conversations of varying degrees of importance. When a person dies, the conversations with those around them cease. Part of the problem for those still living is that that person's contribution to the conversation was part of the construction of reality for those in relationship with them. Their death now means that the reality they were building together can never be finished. There are occasions, it seems, when a person, aware of their impending death, is able to gather their family and friends around and bring the conversations to their close. That process is able to ease the grief that

ensues, but it does not alter the fact that there now has to be a new reality in which to live, one which does not include the one who has died.

Sid was well into his eighties. He had Parkinson's, but more importantly he had Pearl. They had lived the best part of 65 years together, then she died. Sid looked at himself and his new situation and he shut down and died within six months.

Joe, with failing eyesight and hearing, had just prior to my coming to the parish taken his wife back to Britain to celebrate their 70th wedding anniversary. After they got back Grace developed throat cancer and died, but Joe continued on living another couple of years, still active for 90+.

Both men grieved deeply for their wives, they both acknowledged their loss. However for Sid, he said to me – "It's too hard, I haven't got my love to talk to, there's no one left who can help me make sense of anything any more." For him his world had collapsed and he had no interest in rebuilding a new one, so he turned his face to the wall as it were and chose to die. Joe on the other hand saw things differently. There were still things to be explored, learned about. For him the world had not come to a total end and in the time he had left he found something there that allowed him to adjust and keep going.

A family who lost a son through an accident with a rifle in his room put all their grief aside and boarded up the cupboard in his room. There are a variety of psychological theories as to what might be going on, and what best to do. In talking with the father, at the very least he was unable to accept the new reality that his son's death created. His solution was to put dealing with it on hold. Part of his problem was, that in trying to find some sort of meaning for what had happened the old answers did not fit, but no one had given him the tools to create new ones. It also meant that life and its meaning had become distorted, or perhaps better, stunted, and the world he and his wife shared was in danger of fracturing. It was a complicated mourning and grief and ongoing for the whole family, but not one that could be easily navigated through.

*And there's anger in my heart;*

*It's bitter, deep and dark,*

*But for whom or for what*

*It's hard to tell.*

*Is it for blind, uncaring fate*

*That builds bridges far too late?*

*For his life, for his escape,*

*Or for myself?*

*But who the hell am I his life*

*To discount or deny,*

*To say what made him laugh or cry,*

*Or brought him pain or joy?*

*Early strangers we became,*

*And strangers we remained,*

*The man who made his pride his chains,*

*And the sullen boy.*

Similarly, for some who have had loved ones die in situations where the body has never been recovered, there is a certain unrequitedness which no manner of counselling or therapy can really overcome.

What would complete adaptation to loss be in these situations? By whose assessment would the adaptation be complete? I recently took the funeral of one of our pioneer women ministers. She had been married but tragically her husband was drowned and the body never recovered. Her sense of God accompanying her through the dark period of mourning provided comfort and strength for her and coming out of it she saw a path into parish ministry as what she needed to pursue. From what people saw and experienced of her ministry, she found she had an empathy with the many parishioners she ministered to, bringing with her what she saw as a “more mature theological thinking to her life” as a result of her grief.

These examples show that the response to loss and its attendant grief has no clear pattern. The world building and rebuilding image also implies that we do this constantly and that there is no predetermined outcome for how our world built or rebuilt should look. It’s almost like doing a jigsaw puzzle with no frame, no set shape of piece, or part of picture. We make the pieces and paint them into the puzzle as we go.

So what about the Kübler-Ross grief process model with its five stages? Doesn’t that spell it out for us how there is a clear progression from denial to anger to bargaining, depression then acceptance? Well for a start Kübler-Ross was not exploring grief in her work, but was rather discussing some key emotional reactions of the experience of the dying. Agreed, grief was a part of that experience, but it was not the totality of the experience. It was not research but is better described as a popular work of observation and description so that health professionals might learn to listen to what the dying have to tell us about their needs. Secondly, her work showed that there could be up to ten stages or phases observed on the path to death for those aware of their journey. She herself repeatedly warned that many of these “stages” overlapped, might occur together, or even that some reactions could be missed altogether. To emphasise this conditional way of taking about stages, the word “stages” was even put in inverted commas to emphasise their tentative nature.

Two examples might suffice to illustrate. Three years after my mother had suddenly died, my father visited me in Picton along with his sister. She was a fine organist and the church had a very new double keyboard electronic organ so we went up for her to have a play. After a while Dad suggested a hymn for her to play and halfway through we were surprised by him grabbing me and sobbing uncontrollably for a bit. It wasn’t a case of “pull yourself together man”, but rather, as we talked later of how the surprise of hearing a favourite hymn that had strong emotional ties with him and Mum, things I was quite unaware of triggered off that deep sense of loss that he carried with him. That loss accompanied him even into a new relationship which lasted 13 years until he died, but at the same time it didn’t get in the way.

In a similar way, a woman whose husband I had taken his funeral for, found herself surprised four years later when she decided to clean out the back porch. She found a jacket of his and checking the pockets found a handful of wildflower seeds. These he used to spread as he guided people through the lower pastures of the Queen Charlotte Walkway, so that there were always flowers in season. She found herself going into a phase of anger and denial. Was her response one of unresolved grief? It was certainly grief, grief that was accompanying her on her ongoing journey, but what would be meant by “resolved grief?” How long is too long?

There are many other examples of where “stages” appeared out of sequence which have led people to feel they are doing their grief wrong, and with that, going looking for help, for solutions to a perceived problem. I want to suggest to you that comparing the grief journey of the living with the stages Kübler-Ross described of the experience of the dying is like comparing apples with pears, or perhaps even apples with something that isn’t even fruit.

I found it interesting to find an article which tries to throw light on the Kubler-Ross Change Curve which the author says is the most reliable tool to understand change and the stages associated with it. This has been converted into a business model where it can be used by business leaders across the world to help their workforce adapt to change and move towards success. How you get from Death to Success is beyond me, but it shows how we seek models that describe patterns so that we can manipulate our environment effectively, and allow us to prescribe remedies for situations where we don’t fit the patterns.

Having drawn her curve, the author does qualify everything she has just said by writing, “It is essential to understand that we do not move along the stages in a linear direction or step by step. A person tends to move into stages in a random order and may sometimes even return back to a previous stage after a certain point in time.” In my dictionary, “stage” in this context normally means “a point of development” and “degree of progress” indicating a sense of time related linearity.

Granger Westberg in his little book *Good Grief* uses ten different stages in a more helpful way, but even he recognises that not everyone passes through all of them or in the order he maps out, as he was rather describing what he met as a pastor. At the end of his book he cautions that he does not say that the final stage is “We become our old selves again.” Our encounter with grief means we come out as different people. We see and experience the world differently now.

If there are any stages that make sense to me it is a simple model given to me years ago which suggest a way is to look at the energy expenditure in your life. At the moment of bereavement all one’s energy is taken up with simply surviving the loss. Anything unnecessary is put on hold. I recognised that as in the days after Denise’s death I did a whole lot of sleeping, I didn’t attend to food, hair, shaving. Then as time went on a new element comes into life and that is using energy to attend to the necessary chores of living. After a while other things start to happen and you start to enjoy small things. Finally all these sit in balance. For me I recognise that the grief is still present but the energy needed to attend to it is much diminished. One of the reasons I like this is that there are no “rules” about what you must do to attend to the energy you use nor a set direction.

Eric Fromm noted that “To spare oneself from grief at all costs can be achieved only at the price of total detachment, which excludes the ability to experience happiness.” In our haste to pursue happiness we fail to recognise the reality of life and so look for quick fix solutions, and the solution is to be happy. Be wary then of those who rush to prescribe antidepressants to address your grief. Here’s a better prescription: Mourn the death of your loved one in your own way. There is no prescribed formula. You may cry; you may not. Your reactions will be shaped by many things: the relationship you had with the deceased, your personality style, and the support or lack of support you receive from others. Push aside those who tell you to move on, that every cloud has a silver lining.

The idea of journeying came to me reading a book by Tom Gordon who had been a parish minister, a hospice chaplain and chaplain at the Marie Curie Centre in Edinburgh. He used a phrase for the title of his book “New journeys now begin” taken from this Eric Bogle song. That song in itself is a beautiful illustration of what I think I’m talking about. Here are the words of the last verse.

*Without joy, there is no grief;*

*Without hope, there's no belief;  
Without love, Death's just a thief  
Who steals nothing more than time.  
So with love, I scatter him  
To the water and the wind.  
Two new journeys now begin,  
His and mine*

To use Tom's words "For Eric Bogle and his father, in practical and metaphysical terms, in living and in growing, there were two journeys. But new journeys beginning, and the learning and the growing which begin when we are bereaved, starting from that life-changing moment of loss, are common to us all. Bereavement is not an illness to be cured, but a journey to be embarked upon. Loss is not a problem to be solved, but a road to be travelled. Grief is not one stage of life to be coped with, but a series of different pathways along which we have to move as best we can. Such journeys are new to those who are facing loss and bereavement for the first time. Such roads are strange. Such pathways are unfamiliar. Such uncharted stages are dark and frightening. But other people have been along them before us and can tell of how they have managed. Such new beginnings start now."

I can say "this was my experience too" on the death of Denise. All sorts of things from planning meals or trips, or how to live in our new house had been worked on together. But now I was lost – and being lost is about being on a journey whether physical or spiritual, and no longer knowing where to take the next steps. The familiar hand to hold was no longer there. Searching for her spirit was part of the grieving, for searching is about the pain of the loss and the love that has mattered so much to me. That searching never stops, because the loving still remains. I did have some folk who were happy to tell me what needed to happen next, but I was on a new journey myself and some of what was offered did not fit the terrain I had to travel. But not being bound by the need to complete a process meant I could discard those things which either did not fit the new world I was starting to construct, or weren't needed on the journey into this new land.

As I've talked about this metaphor with others I've had some interesting responses. From those who have been grieving, many have embraced the image warmly, finding it gave them permission to do what they wanted to do. There have been those who have questioned me about the consequences of taking a dead end. When I say that is all part of the journey, including our journey when we are not in grief territory, they shrink from that, because, I think, they see life as an already mapped out pathway. It is five years since Denise died and recently we gathered as a family and had a meal together, something we haven't been able to organise at this particular time of the year for all of us. Each of us have travelled our own journey with our grief, with our different experiences of loss.

I think we all look for markers or milestones along the road as a way of making sense of our living. We want to know we are on the right track, and on our journeys through time look for chronological markers – 1 month, 1 year... and five years seems to be one of those markers.

As I talk with my children, I find the things they miss are different to what I miss, the loss they feel, different to my loss, and similarly the ways we respond to these things. It means our journeys with

our grief have been and still are different journeys, that there is no pre-drawn path, no map that is already drawn for us to follow.

Yet we are not alone – others have traversed these pathways, started from the new beginnings that grief, loss and bereavement opened up to us. Such pathways are strange, but we can, and others can, tell how we have managed. We can also listen to others tell how they began their journeys and offer them our encouragement. The biggest thing that I have had confirmed in my own experience, and the experience I have had accompanying others on the start of their “new journey” is that to love and to be loved means we will experience the pain of loss; that we will know grief because we know what love means; that we understand bereavement because we have given ourselves in love and known gracious love in return. Loss and grief walk hand in hand with love and joy. These are not pathologies to be fixed, or problems to be solved but part of life that is best held in the soul.

Have I assimilated my loss? I think I would rather say that as I have journeyed with my grief I have been transformed. Yes there is an integration that has happened, but the loss is still there, yet the world I now live in has room for that loss to be carried with me as I walk on my new journey daily.

*... So with love, I scatter him  
To the water and the wind.  
Two new journeys now begin,  
His and mine*

## Dr Brian Ensor: The Medicalisation of Death

### *Introduction:*

There is a saying "You specialise in your area of greatest weakness". I found that in a calendar and stuck it up on the office wall to keep me humble. There is some truth in it. You can concentrate on the area that most concerns you, that you are most afraid of, that you most want to control.

One of my earliest memories is as a very young boy seeking out my mother at night, because I was scared of dying. I am not sure what triggered that one, perhaps just normal development, or a dead bird or something. I was a sensitive young thing. Anyway, she comforted me and in the end I became a palliative medicine specialist. Not because I understood death or because I particularly comfortable around death, it still troubled me. Besides, there is not enough heart problems in my family to become a cardiologist, and not enough madness to become a psychiatrist, but we have this very strong family history of dying. So I do palliative medicine out of self-interest, every experience has a bit of 'that could be me' in it.

Initially I trained in General Practice. And I did okay. What pulled me into palliative medicine was the team nature, general practice tended to be very doctor-centred in those days, the ability to have time to think and plan and discuss, and the necessity of hospice work, were very attractive. Back in the 1980s hospices were just starting, and the dying patient was being recognised as a bit of an orphan in the medical world. The medical system had sympathy for the plight of the dying of course, but no-one really wanted to get involved. They had their own business or busyness to look after. So in communities around NZ, people in the community started to say 'we need a hospice'. Sometimes it was a nurse, like at Te Omanga Hospice in the Hutt where I started, sometimes it was a religious order, like the Mary Potter Hospice in Wellington where I came from. Sometimes a

community group, like at North Shore Hospice where I worked. And of course our own Margaret Broad, who had trained as a nurse, here in the Waikato. Doctors were involved of course, sometimes up front and leading. Prof Grey in Wellington, and we looked to overseas doctors as our inspiration. Cicely Saunders in London, Balfour Mount in Canada, Derek Doyle in Scotland. But it was never a medical lead movement in NZ.

Rather there was a bit of a scramble to get doctors to take an interest in hospice work. To get involved with patients who could not be 'fixed;' so to speak, who were likely to die in the coming few weeks or months, and who wanted to concentrate on their quality of life, and not on hospital based things. In the beginning it was almost all cancer, with a little bit of Motor Neurone Disease or kidney failure patients. The doctor's job was to find out what the most pressing medical issues were, whether that be pain or breathlessness or confusion or constipation, and help with those symptoms. We would go over patient's medication and stop what was not needed. We would liaise with their other doctors and make sure the patient and family understood what was happening and what their options were.

And always in the context of a multi-disciplinary team of nurses and counsellors and social workers and spiritual care, because just a doctor is woefully incapable of meeting all the needs of a patient and family who are facing a death.

So here is the question. People have always died. There is nothing new in dying. And yet now it seems you cannot die without a full compliment of health professionals to accompany you. How did that happen? Is it necessary? Really? What has changed?

Have we medicalised death?

#### *Four Big Stories*

There are a number of big stories about the medicalisation of death, and Ivan Illich, the Catholic Priest come Academic come Philosopher is behind a number of them. His books "Medical Nemesis" published in 1974 and updated, is one I have not read, it is not easy reading, but which is much discussed. I do not believe you will have a lecture about the Medicalisation of Death without reference to this man.

He talks about Medicine as a Monolithic Religion. About social problems ending up in hospitals. About the total sum of medicine in the wellbeing of humanity being in the negative. He has some points which we will review. It is safe to say that Illich was met with quite a bit of harummphing and ill will from the medical profession / industry over the years.

Anyway, using some of his ideas, and some other miscellaneous ideas. I have decided there are four big stories about the medicalisation of death.

Why four? Because at medical school I was taught about the four elements of health, proposed by Mason Durie, and this is taught to every medical student since. Te Whare Tapa Wha, or the four walled house, says that health consists of four things. The body, the mind, the spiritual and the family. Tinana, hinengaro, wairua and whanau. The four stories shadow these four walls. The medicalisation impacts on all of health.

The **first** story which is heard a lot today concerns the medical industrial complex which is quite Ivan Illich-y. Medicine is an industry, and as such is interested to medicalise our lives for profit. By making the normal unacceptable and then framing it as a medical problem which requires a medical solution, a profit can be turned. Women's issues. Childbirth and menopause. Weight and body image. Aging. Aging skin, aging muscles, aging brain.



Certainly those of you into conspiracy theories will be well versed in this story. And even for those of you who aren't.

At its roots, it is not particularly contentious in my mind. Medicine in its broadest sense is an industry and not necessarily different from any other industry. It looks for things that people might need, or want, or often, are fearful of, and supplies it for a price. If there are two motivations, love and fear, then fear is ripe for medical picking. And it is successful. Is it altruistic? I think there is certainly some altruism in there and health has more than its fair share of people who are genuinely seeking the betterment of their fellow human beings. Absolutely. But it is operating within a market.

Which means, most obviously in cancer medicine, the market can develop products that only some people can afford. You might drive a Bentley, I might drive a Morris, she might drive a Porsche, they might have shares in a Nissan. We don't particularly care. When we have a terminal illness, the fact that this country funds this treatment, that country doesn't, he can afford this technology, I can't, all becomes very important. This is the stuff of headlines and lobbying. It matters a lot.

These are real people who we know, or we can identify with. There are complex ethical discussions around the moral value of extending few lives against benefitting the many.

Another part of this story, I think, is the self-serving nature of medicine, which may not be for money, but status in another way. The patriarchal nature of medicine, profoundly challenged in NZ by the Cartwright Enquiry, 30 years ago this month. Medicine is an industry which provides profits, and medicine is also a profession, which provides status.

And the last side effect of the market on medicine is this idea that the body is the thing that should be fixed by its owners. Sheeting back responsibility to the person.

The **second** story in the medicalisation of death you might trace right back to the Renaissance, or more specifically the Enlightenment, when we decided we would become masters of our destiny and not mere pawns of the gods. We would understand the world, control and manipulate our environment for our own benefit. No longer would be merely players, on the stage, with our exits and entrances, to borrow from *As You Like it*. No, we would be authors, like Shakespeare. None of this seventh age sans teeth, sans eyes, sans taste. We will have teeth, we will have our cataracts done, and yes, we will have taste.

This story is about the rise of the individual, and the need to be in control. It challenges the idea that suffering is inevitable and we must bow to the natural order of things. 'Stuff the natural order of things', says Enlightened man, 'I will not die at the age of 40 like my old man. Who never really got old. I have at my disposal a system of screening, investigations, interventions and operations that means this will not happen to me. My life is not preordained, my life is in my hands. And by 'my hands' I mean in my harvesting of the fruits of medical and allied sciences'.

All good, but this need for control asks medicine to offer control over illness and suffering and life.

It asks more of medicine than medicine is equipped to deliver.

This second wall of Te Whare Tapa Wha, the emotional, Hinengaro as at the seat of our behaviours. So from our bodies needing to be fixed, this story is about our emotions driving our behaviours.

What are these emotional drivers? There are lots of different models, the one I like is David Rocks' SCARF model. The anagram is for:

Status (not about the Bentley so much as the need to be recognised as a person).

Certainty (the need to know what is happening).

Autonomy (the need to have a sense of control).

Relatedness (the need to be in relationship with others) and  
Fairness.

These very strong drivers which, like so many border collies, shepherd us into the medical pen, where we believe these emotional needs may best be met.

So this story tries to explain how much medicine is looked to fill our emotional needs, not just when we are unwell, but when we are contemplating our life generally, and contemplating our vulnerability to death specifically.

The **third** story is linked, and is the arc of religion, our interaction with the transcendent and the mysterious. Wairua. Where we ask the Why questions. Why do I have cancer? Why am I suffering?

Once we looked for God with a telescope. Now, Medicine specifically, uses a microscope in the belief that by paying attention to finer and finer details, we will come to an understanding of the whole. So for the Why, the meaning and perhaps even the salvation we look to the scientist or the doctor. To understand suffering and happiness we ask the neuroscientist. After all, our neurotransmitters are the source of feelings and emotions and perhaps, spirituality. Again, I discuss with medical students that question "Why do I have cancer?" The temptation is to talk about risk factors and DNA mutations and exposure to carcinogens. We just need to be aware this might be a spiritual question. "Why do I have cancer?" Why does the universe hate me? Why are my family being punished? What have I done to deserve this? Remember fairness as an emotional driver?

We have some sort of expectation that life will be fair for us.

In a world which encourages a spirituality where meaning is invested in individual experience, death does not naturally integrate.

One might also examine whether medicalisation has replaced rituals? There is a gap left where religious ritual could bestow meaning, the noting of the seasons, the preparation of the soul for death, the anointing of the sick, the last rites in the Christian tradition. Death often comes surprisingly slowly for many, and that dying can seem an empty and worthless time to some.

And healing. What is healing in the setting of the terminally ill? It is an important concept, one that medicine does not discuss.

In my work I see this manifest in refusing to consider death, an overblown belief in the power of medicine as mediated by the doctor.

And the final story, perhaps more practically observed, the Whanau is the story of our families.

They look different now, and they work differently now.

This is big, and brings in all the socio-demographics that we love. Including how we die. There is one statistic that illustrates and evidences what I am saying. Where do we die? More and more, we die in Aged Residential Care (ARC), in the hospital wings of your local Ryman or Bupa. In the decade up to 2010 we have the figures of place of death from work Prof Heather MacLeod has done for Hospice NZ. Women are more likely than men to die in ARC. For 10 women that died, 4 will die in ARC, 3 will die in hospital, 2 died at home, and the other woman was equally divided between hospice and other, like dying in road accident or in jail. So that is 4 in ARC, 3 in hospital 2 at home, and one divided between hospice and other. Do that for the elderly women, over 85 and 6 out of 10 died in ARC. For men of any age, about the same number died in hospital as in ARC, 25% each ways, about the same likelihood of dying in a hospital as a woman. Significantly more likely to die on the road or from a sudden or violent death. For old men, if you remember 6 out of 10 women where dying in ARC, well slightly less than 5 out of 10 men died in ARC. They were more likely to die

in hospital or at home than women. So those numbers are up to 2010, and I think they are the start of a trend that will increase. Although less chance if you are Māori or Pacific.

Why are people dying in ARC? Two things top the list. People suffer multiple diseases that make them frail, often a combination of diseases of the brain, the heart lungs and kidneys. People refer to this as dwindling, slowly becoming more frail and susceptible to injury and illness tipping you over. Frailty is a medical diagnosis. For the most part now we see death coming, for better or worse.

And secondly there is not the family support to enable them to be at home, specifically a spouse. If you die first, you are more likely to be at home or in an acute hospital.

You can look at the Socio-demographic changes that are upon us, as the pyramid of few very elderly on top of the good number of workers and the many children becomes almost inverted, as we worry about who will look after us in our old age. And if there are children, where are they? Families disperse now and move out. No longer does Granny live in the back bedroom as happened a few generations ago. Hence there is the relatively recent rise of the Retirement Villages, each containing their own level of care needs, including hospital wings.

Institutional living has its own rules, its own priorities. Atul Gawande who is a New York surgeon, and a prolific and very good writer, wrote a book called *Being Mortal*, which is one of your must read books, where he examines death through both a personal lens of his family, and the an analytical lens of his professional as a surgeon. A major point he makes and illustrates so well is that people are directed into Residential Care for their safety. It is unsafe to be at home. In care, at least they will be safe. They may not want to be safe of course, lot of stories about people escaping the confines of care to be unsafe, (the movie *Edie* and *The 100 year old Man Who Climbed Out A Window* etc.)

Illich also pointed out, that what are essentially social problems, frail elderly living in their own, often unsuitable and somewhat isolated houses, are medicalised. You will have a medical assessment to go into funded care and your future is based on what the doctor or nurse doing the assessment says. The Institution will then be audited as to how safe you are, rather than on your quality of life.

Now I must say that for the sake of making a point, I have not given a rounded view of ARC, there are lot of very good and exciting things happening in ARC, a lot of very good people working in the industry, and there you go.

So the four big stories. The story of the medical Industry, the story of the investment of our need for control over our lives into medicine, the story of the supplanting of much of our spirituality into the world of medicine, and the story of the changing family and the community.

Te Whare Tapa Wha. The four pillars of health affected by this medicalisation.

Can we summarise some of this, from my point of view?

### *The House Model*

The second half I want to use this metaphor that I have called the House Model. I have used it mostly to talk to Med students.

It takes the fact they are visiting a patient in the house, and imagines the patient leading them around their house, talking about the different rooms and what is changing in them.

It is a metaphor, so they aren't really going around the different rooms, and some of the rooms that we like to talk about don't really exist. It works best when they get a little imaginative.

We always start off in the Parlour

Then we go anywhere. My favourites include the kitchen and the bathroom and the attic and laundry.

So for instance in the kitchen we talk about changing nutritional needs, changing appetite, but also the meaning of meals and the dinner table, and how we show love and acceptance. It is all in the kitchen. In the bedroom we talk about sleep and intimacy. In the toilet we talk about dignity.

For today, I want to use that metaphor to explore how medicalisation of death changes the patient experience. We will poke our nose into a few rooms:

- In the sick bay we talk about our physical disease.
- In the study we talk about our sense of autonomy and control etc.
- In the family room we talk Whanau.
- And in the chapel we talk about healing and transcendence and hope.

### *Let us start in the Sick Bay*

Medical students don't really have sick bays, they have some Panadol in the bathroom and some plasters in the kitchen. Our patients have really big sick bays, sometimes their entire life seems to be lived in the sick bay. Which is a point worth touching on.

Doctors can do their jobs by spending the briefest of moments in the Parlour forming a relationship "Hi, my name is Dr Bob, and I will be your doctor for the next half hour", and then diving into the sickbay where all the good stuff is, the blood results and the investigations and the pathology slides and drugs etc etc. We feel at home there. That is what we do.

Big problems. We don't know the rest of the house, and we doctors assume that the important stuff is in the sick bay, and we make decisions based on that, which doesn't work. We make the mistake of thinking that the sick bay is in our house, and we control it, when we don't.

Sometimes this reaches the point the point of a fake sickbay, to extend the metaphor to breaking point, when it actually is not the patient's actual sick bay at all that us doctors are meeting them in, but something that is more akin to a room outside on the road, which only has a passing relevance to the patient's real sick bay, which is in the house and filled with very different medicines. We might be talking about cross-cultural experiences here.

The sick bay needs to be in the patient's house to have any relevance. The worst medicalisation of death is when the patient is actually divorced from their life. They are not in their house at all, physically or metaphorically. Perhaps dying in Intensive Care Unit. They have lost access to the rest of their house, the rest of their life, they are dying away from home and according to some-one else's rules.

As an aside a lot of this sort of critique concerns the US system, where medicine is clearly financially incentivised, which does not happen in NZ. In the NZ public hospital system, there is not a financial incentive for doctors to treat you. Quite the opposite. What is in shortest supply is time, and here the risk is not having time to go through all the options and understand things. The risk is on pitching up to ED is that the protocols are followed rather than having the time and opportunity to speak to the patient and family and other medical carers etc. Hence the importance in having those sort of discussions earlier, I am thinking of the Advance Care Planning. Discussing what your priorities are in your life, whether they be more time, the ability to interact with people, the ability to go to sea. This sort of thing.

The sick bay is the best resourced room. That is a problem in some ways. We can talk about that later. Once you start to move your priorities out of the sickbay, resources are more scarce. You may have heard the med system is designed to stop middle aged men dying. There is some truth in that. Mental Health is in the headlines at the moment as a part of the health service that has not received due emphasis and resourcing. Palliative care also runs under the priority radar specifically because we don't save lives. It does not command expensive drugs or technologies that excite industry. There is no race to make dying the best it possibly can be.

Pros and cons - a pro is that the community is still involved.

We need to up our use of technology in the sick bay. Waikato has the unique situation of having 200,000 people living outside the major metropolitan area. We should be using Telemedicine and iPads and perhaps remote controlled pumps to deliver medicines, there are some benefits in technology that we should be picking up on.

Palliative care has a key role in providing an overview from this room. Explaining what options there are in the sick bay and linking it back to the rest of the house.

We need to be seeing medicine as an offer, not a contract that we have already signed up for.

### *Next room is the Study*

This might be the most important room in my culture. It is about Cognition.

Independence. Work. Control. There is a certain synergy here with medicalisation, as we are hunting down treatments on the internet. For many, including the medical students and myself, this is the biggest room in the house. Which is why synergies exist, doctors understand people who live in studies.

Being so invested in this room has its Difficulties. Including not having a Plan B, and being too invested in the Plan A. Actually facing that you have to let this room go, if not shift out all together. This is anathema to some, and the euthanasia debate is firmly rooted in this room.

Our best bits might be in this room and 'we are losing them' is a common experience. We have difficulty with acceptance and loss of control, and hence loss of dignity etc. and prioritisation of healing.

### *Family Room*

The dispersed and aged family - is the family room empty for some now?

Is it filled with professional carers?

Are families overseas, and showing their love by demanding interventions? These may be out of keeping with reality but arise out of love and concern. Maybe safety is their priority, as described by Atul Gawande.

The concept of Resilient Communities comes in here! It takes a village to help someone die at home, it is not resourced by the government. It may need some training, even some expertise in some areas, but it is certainly possible. We need to strengthen communities and perhaps they can fill in where the family used to be in the past.

### *Ballroom*

This is about glamour and hopes and dreams. Hopes are very important, though they change. Hope for a cure may change to hope for a remission, hope for longer, hope to get to a wedding, hope to have time in the garden, hope for a peaceful death and a strong legacy. Without hope people might find themselves in an underground bomb shelter, in the dark, waiting to die. We have to understand the importance of hope. And we are still allowed dreams, and doctors should be able to

recognise dreams and not squash them. Doctors concentrate on Reality. But 'Everything in Moderation' my grandmother used to say, and reality is included in that. You can take only so much reality.

### *Spirituality / Garden*

People have a spirituality, and sometimes it is manifest in a prayer room in the house, or an altar or shrine, for others they may find their place in the universe when they are in their garden, or staring at the stars. I use the Chapel as the name of this place, but it could also be known as the garden. Where we are aware of the transcendent, and some consciousness of our own place in the greater picture.

Historically religions have dealt with issues of suffering. The answers that religions had may seem strange and unfamiliar in this new secular world. We have lost any explanation for suffering, certainly any value in it. To quote from Illich literature. "We have come to believe that technology can eradicate all human suffering and provide unblemished and everlasting happiness. We have paid the price for this irrational expectation with our autonomy, our dignity and our ability to endure" Joanna Moncrief (<https://joannamoncrieff.com/2016/04/18/limits-to-medicine-re-visiting-ivan-illich/>)

They have recognised seasons of life and arranged rituals around it.

They have aided preparation for dying for those that are dying and those around.

They have dealt with blame and guilt, things that can be exaggerated by our modern tendency to blame things and control things.

### *The Dying Room*

It all comes together in what I call "the Dying Room".

We all have one. Professionals have a fake one - we can talk about that.

The room where you go to think about your death, and where you will eventually die. We talk about what sort of room it is. When should you start going in there?

I think most children will go in there when they learn about death and themselves.

Is it a place you go in with your spouse, or your minister or your friends? What is it furnished with? Do you have a sort of Dante's inferno vibe going on, or something a little more pastoral? Is it a welcoming room, or is it scary? When did you last clean it out?

They do need cleaning out. Spiritual Carers may have this role at the hospice. The aim is to have it welcoming. Do I want it to be fighting room? You could I suppose. Do I want someone reading Dylan Thomas' 'Rage, rage against the dying of the Light' to me? No. Do I want a choir singing? Probably not. Others will.

What does it smell like? I would like mine to have a faint smell of fresh cut grass. I would like to have my old faithful dog there, and my wife. My children, if they have nothing better to do. The dying room is a useful metaphor to consider.

My reason to bring it up today is to ask the question - is it medicalised? Would I want a doctor and a nurse in the room? Would I want a lot of machines? I know I am likely to have a commode and an air mattress, but I am not sure I want a lot more?

I do want very good medical care. I want someone who knows me as a person, and is not afraid of being reasonably straight, and knows who to ask if they don't know something. I want nurses with a

sense of humour, and who are not too fussy. And not too chatty. The place is perhaps not so important to me. It is for some.

My experience of going inside other people's dying rooms with them is thus. The priority is peaceful relationship. There has to be room for loved ones. (Although some do choose to die alone.)

There has to be safety.

In the end all else is lost, and you have a Dying room. Get in there and sort it out. Nobody can promise there is no suffering, and the medicalisation of death isn't going to fix that, helpful as it may be in mitigating all sorts of other problems. Dying is a very personal experience, please don't look to medicine for all the answers, it will fail at that.

So we have looked at four stories about the medicalisation of death and tried to illustrate some of the effects by wandering around our metaphorical life / house, looking at how changes affect us. Dying may not be as simple as it was, it can certainly be more prolonged, and people have more time to prepare for it, if they want to. A lot of our life has been medicalised, our challenge is not to listen too hard to medicine, and expect all our answers to come from medics.

In the business of palliative care, I think we have a lot to offer, and we need to be assiduous in applying the right sort of medicine at the right time. But don't live in the sick bay, our lives are so much more than that. Keep hold of hope and dreams alongside your reality, foster your relationships and family, be prepared to relinquish total control, search the past for ritual and meaning. Don't accept a musty unwelcoming dying room. Refurbish.

Thank you.

#### *Other references:*

Gawande 'Being Mortal' <https://www.amazon.com/Being-Mortal-Medicine-Matters-Kushiels-ebook/dp/BOOJCWOBCY>

Jonasson 2009 *The Hundred Year Old Man* [https://en.wikipedia.org/wiki/The\\_Hundred-Year\\_Old\\_Man\\_Who\\_Climbed\\_Out\\_of\\_the\\_Window\\_and\\_Disappeared\\_\(film\)](https://en.wikipedia.org/wiki/The_Hundred-Year_Old_Man_Who_Climbed_Out_of_the_Window_and_Disappeared_(film))

Edie 2017 film [https://en.wikipedia.org/wiki/Edie\\_\(2017\\_film\)](https://en.wikipedia.org/wiki/Edie_(2017_film))

Illich, Ivan 1976 *Medical Nemesis the expropriation of health*

#### **Beth Richards: The Value of the Funeral**

Show me the manner in which a nation cares for its dead, and I will measure with mathematical exactness the tender mercies of its people, their respect for the laws of the land and their loyalty to high ideals. (William Gladstone, British Prime Minister, 1809–1898)

#### *Life has got busy*

We have filled our hours with more and more things, activities and striving to make ends meet – but in doing so have we filled it up with busyness or with things that matter, things that impact our lives and the lives of others – things that enrich our lives and our relationships? Or are we busy just making ends meet, or involved in activities that have no long-reaching effects?

Today we often live behind high fences, in gated communities or apartments – all physical barriers to us interacting with community.

I think of value in this way – Value is the regard with which something is held: to deserve; the importance, worth, or usefulness of something.

In order to consider the value of a funeral, let us first consider the function of a funeral at its most simple:

It is a platform upon which to physically and psychologically farewell someone and allows us to join with others as “community” in acknowledging the passing of a common friend, a relative.

It is an opportunity to show support to a grieving person or family.

I have always had an interest in grief and the effects of chronic grief and grief resolution has been a motivating factor in my work in the funeral industry. Grief is not something we get over, but rather something that done well, becomes part of the fabric of our ongoing life.

Thirty years ago New Zealand funerals were about half an hour long, usually led by a minister of religion, had two hymns and perhaps some short words about the deceased. They were usually held in a church, a crematorium chapel, or in some cases, the funeral Director’s chapel.

Today we have learnt to personalise funerals.

They are held in many different locations – from churches to wool-sheds – a location that has relevance or convenience for the family.

The funeral service may be led by a minister of religion, a celebrant or a family member – there is no legal requirement around who can do this, unlike marriages, where the person must be licensed.

The funeral may or may not have some of the following:

- A casket that has been decorated to reflect the life of the deceased – or perhaps have been signed and messaged all over by friends and relatives.
- Music of any genre
- Poetry
- Picture shows that give a pictorial view of the person’s life
- Eulogies presented by family and friends – often with amusing anecdotes

Service Sheets – giving the mourners a photo to take home with them – these are often kept, as I can testify to - when visiting families out come all the service sheets they have collected over time.

- Balloons
- Fly-bys
- Bagpipes
- Participation of guards of honour by groups that the deceased may have been part of.
- Children are included rather than excluded – allowing them to experience the cycle of life and the natural part that death plays in this cycle.
- Memorial Books
- Releasing of doves or butterflies
- Involvement of the family in dressing, or filling in the grave
- Use of symbols or articles relevant to the person – i.e. a bridle, racing silks, rally driver helmets
- Motor bikes as outriders to the hearse
- The use of a quad bike and trailer to take the casket from the chapel to the graveside
- Or as in one case a horse float, with the horses leading the way out in front.



Alongside these ways that people are choosing to honour and remember their loved ones, there is also an increase in the number of people opting not have a funeral service:

There could be many considerations for this: and I do not wish to judge the people that make this choice, but their reasons include:

- Financial considerations
- The deceased did not want “any fuss”
- “there’s nobody left that knows my mother” – all her friends have gone
  - Everybody is so busy, we don’t want people to feel they have to come

and on and on it goes. If cost is what determines the value of our ceremonies, then maybe we should look at weddings. Why is it that we appear to see value in wedding ceremonies for marriages that may or may not last, but fail to see the value of the funeral.

I have read some interesting literature recently written by people who have had friends or relatives who have chosen this option – I would summarise their comments by saying without exception, they have felt bereft, had no opportunity to say goodbye and were left in limbo!

Back in the early 90’s I assisted many mothers who had a still born child back 30 – 40 years ago when the custom was to bury the baby in an unmarked grave, and often the mother had never seen her baby or held it. This was a sacred journey to share with these mothers and I came to know without a doubt the importance of knowing, being involved in and having the opportunity to say goodbye to our loved ones, whatever the age.

When the Kowhai lawn was refurbished at the Newstead cemetery, Karen and I were present at the opening of the new monument. Not only was it a chance to stand alongside families we had cared for, but also to hear the stories of bereft mothers. One stands out for me:

There were three women – a Mother with two daughters – the mother was 80 and still mourning for the baby boy she never saw, held or knew where he was buried. She was there because this was a way of participating in a ceremony for the child she never formally fare-welled.

Having had the privilege of working with these mothers and in some cases finding out where their babies had been buried, I am left in no doubt as to the importance of the funeral, in whatever form it takes, and the need for many people to have a touching place – a place to go, a place where the name is recorded or the ashes are scattered.

The professional bereavement, caregiving and scholarly community put forward much evidence of the value funerals play in the grief journey.

The funeral service, if done well, can be an important foundation for good grief resolution

Kenneth J. Doka in his book *Disenfranchised Grief* says “a significant body of literature affirms the therapeutic role of funeral rituals. These benefits are enhanced when the funeral ritual allows personalisation and participation by significant others.” In New Zealand we have developed a funeral culture that does just this, and does it well

Ceremonies can help ignite a passion for change. Sometimes death comes after great injustice and the funeral ceremony helps galvanise the effort to create change. For instance the attendance at the funeral for a young mother killed by a drunk driver, or the child who dies as the result of head injuries with no protective helmet while riding his bike.

Whether the ceremony incites a generation to action or not, funeral ceremonies remind us of the precious, limited amount of time we all possess. Nothing provides as stark a reminder of the fragility of life and the finite nature of time as much as seeing a friends casket being borne away.

The ceremonies of bereavement remind us that our own pain of loss is shared by the community. Funerals, memorial services and any other observances we share in the face of death, possess important social meaning that goes beyond simply getting the dead buried or cremated. These ceremonies remind us all of the ancient notion that when someone dies, it is important to stop what we are doing, turn aside, and note the fact that our hearts are heavy, our support for each other is unwavering and our loved ones life is worth remembering.

Ceremonies provide stability and order in the chaos of early grief

They help confirm the reality of the death

They help us validate the legacy of our loved ones

They give caregivers an opportunity to acknowledge the people they care for, when families are unable to do this

They can consider the family who live in a different town to their elderly relative. It is possible they have no idea of network of connections and friends in the community their loved one lived in.

Ceremonies reassure continuation of the society.

Ceremonies matter, ceremonies heal.

There are a growing number of people choosing to have their loved one removed and instantly cremated. There are those who say this is a more sophisticated way of dealing with the death of a loved one and it is seen as being less stressful on the family. All too often this is a denial of death and a loss of the healing process of the funeral.

Ceremony can speak for us when we have no words to say. I read the account of one of the recovery workers in the Oklahoma City bombing. He said the thing he will remember the most was a certain teddy bear. The families of the victims would gather at a chain-link fence that was erected to keep unauthorised personnel away from the danger. They wanted to be as close as possible to their loved ones. The workers felt the presence of the families and wanted some kind of contact, some means of comfort. One teddy bear was chosen, and every time a worker came out of the building he or she would hug that teddy bear. At certain times each day that teddy bear was taken outside the fence so the families could also give it a hug. In that simple ceremony they found comfort and connection with their loved ones. Ceremonies matter, ceremonies heal.

Often after a death the first step in the grief process is to establish the personal significance of the person. It is almost as if we must inventory the loss before we can grieve. We need to talk about that person. I read a book on long term grudges. Grudges happen because someone gets hurt and no one would let them establish the significance of that hurt. We need times of remembering who the person was and what they meant to us. We do not know what we have lost until it is gone. These remembrances hurt and yet they heal, for they are establishing significance so we can move on.

Adding to my argument and conviction is my personal experience six weeks ago when my husband died and my family and I were surrounded with so much love and kindness, from a wide variety of people. They sent cards, bought food, sent flowers, wrote letters, did shopping, visited, and shared with us at the funeral as we honoured and fare-welled our husband, father and grandfather. These expressions of love and support and community have assisted us tremendously at this time as we walk this pathway called grief.

Let's keep honouring our dead with our rituals, love and support the bereaved, and do our part to making our community ties richer and stronger.

## K-M Adams: Funerals - A Time of Grief, A Celebration of Life

When I was asked to speak here today, my first thought was of course. Lindsay is one of this world's good guys. He gives a lot personally and professionally so if someone like that asks you for something, my first instinct is to say yes....

I am not an expert but I can share with you the experience that I've had guiding hundreds of families as they prepare for a funeral. And then helping them through the day itself. And I have observed the healing process of a funeral, I understand why things happen the way they do.

These are my thoughts and opinions, formed over the 7 years I've been working as a celebrant. I'm going to outline what a funeral service should do, I hope this is of some use to you...

As a secular celebrant I do all kinds of ceremonies. A lot of families don't want, and I quote "religion to take over" or they don't want any mention of religion whatsoever.

Or, no mention of God but we will say the Lord's Prayer at the end cause that'd be nice and everyone does that don't they? To services that have hymns, prayers, Bible readings, blessings and are almost a church service except they're not held in a church or run by a priest or a vicar.

As a celebrant one of the first questions I ask is, was there any religion? I also explain to my families that a funeral is two-fold; it is to show respect for the person who has died, to reflect and honour their life, and it is also to comfort and support those who are left. So the Service needs to allow for the incorporation of faith and beliefs about life and death from both the deceased and the mourners.

*"When words are inadequate, have a ritual." Anonymous*

Rituals are symbolic activities that help us, together with our families and friends, express our deepest thoughts and feelings about life's most important events. Birthday parties honour the passing of another year in the life of someone we love. Weddings publicly affirm the private love shared by two people.

The funeral ceremony, too, is a public, traditional and symbolic means of expressing our beliefs, thoughts and feelings about the death of someone loved. Rich in history and rife with symbolism; for instance when the coffin is carried it is always carried feet first, flowers on a coffin, the flowers signifying the start of life, implying a hope that there is new life after death, If the family are not religious and there is no hymn or reading, I often suggest a poem to open the service – the poem can set the tone for the service the family wants.

These are all rituals helping us acknowledge the reality of the death and encouraging the expression of grief in a way consistent with the family's or culture's values, faith and beliefs about life and death.

### **Funeral Ceremony Part 1**

The first part of the Funeral Ceremony is acknowledging the reality, the finality of the death. This has to happen if we are to move forward with our grief. Often this happens in two phases. First, we acknowledge the death with our minds; we are told that someone we loved has died and, intellectually at least, we understand the fact of the death. Then, over the course of the following days and weeks, and with the gentle understanding of those around us, we begin to acknowledge the reality of the death in our hearts. This is one of the basic purposes of having a funeral ceremony.

Intellectually, funeral ceremonies teach us that someone we loved is now dead, even though up until the funeral we may have been in unconscious denial. Before the funeral, we can keep ourselves very busy, there can be a lot to do. We contact the funeral home, set a time for the

service, plan the funeral ceremony, talk to the celebrant/priest, view the body, perhaps even choose clothing and jewellery for the body; intellectually we cannot avoid acknowledging that the person has died. But sometimes it's not till the funeral service itself, when you walk away from the coffin for the last time, or watch as the hearse drives away, or see the coffin being lowered into the ground, that we are witness to death's finality.

## **Funeral Ceremony Part 2**

Move toward the pain of the loss.

As our acknowledgment of the death progresses from our head to our hearts, we start to embrace the pain of the loss which is what has to happen if we are to heal. Healthy grief means expressing our thoughts and feelings, and healthy funeral ceremonies allow us to do just that.

I can't tell you the number of times I have been told that "so and so, didn't want their funeral to be sad!" "This can't be a really morbid occasion, because they were a really bright, happy person, so the service has to be fun and happy!"

*This sounds like a really obvious statement, but people tend to cry at funerals.*

This is because a funeral ceremony forces us to concentrate on the fact of the death and on our feelings, often excruciatingly painful, about that death. For at least an hour, sometimes longer you are not able to intellectualize or distance yourself from the pain of your grief. You can't get up and make a tea or coffee for everyone or go out to the shed and bang a piece of wood. To their credit, funeral ceremonies also provide us with an accepted place for our painful feelings. They are perhaps the only time and place, in fact, during which we as a society condone such openly outward expression of our sadness.

That is not to say there can't be laughter at the Service because to heal in grief, we must shift our relationship with the person who died from one of physical presence to one of memory. The authentic funeral ceremony encourages us to begin this shift, for it provides a natural time and place for us to think about the moments we shared - good and bad - with the person who died. Like no other time before or after the death, the funeral ceremony invites us to focus on our past relationship with that one, single person and to share those memories with others. The best funerals have handpicked speakers sharing stories about their times with the person who has died and remembering the person's characteristics that he or she most prominently displayed. This is where the laughter can come as you fondly recall special times. There is nothing quite like laughter through tears and there is no pain so great as the memory of joy in present grief.

I've also found families enjoy having photo memories as a time of reflection – a slide show of photos of the deceased and family members over some favourite music. Speakers sharing anecdotes and photo shows - this is helpful to mourners, for it tends to prompt more intimate, individualized memories.

## **Funeral Ceremony Part 4**

Develop a new self-identity.

Another primary part of the Funeral Service is the development of a new self-identity. We are all social beings, our lives are given meaning in relation to the lives of those around us. I am not just K-M Adams, but a daughter, a sister, a wife, a mother, a friend. When someone close to me dies, my self-identity as defined in those ways changes.

The funeral ceremony helps us begin this difficult process of developing a new self-identity because it provides a social venue for public acknowledgment of our new roles. If you are a parent of a child and that child dies, the funeral ceremony marks the beginning of your life as a former parent (in the

physical sense; you will always have that relationship through memory). Others attending the funeral are in effect saying; "We acknowledge your changed identity and we want you to know we still care about you." Having supportive friends and family around us at the time of the funeral ceremony helps us realize we literally still exist. This self-identity issue is illustrated by a comment you often hear the bereaved make: "When he died, I felt like a part of me died, too."

### **Funeral Ceremony Part 5**

Search for meaning.

On a very fundamental level, the funeral Service reinforces one central fact of our existence: we will die. Like living, dying is a natural and unavoidable process. (We Kiwis tend not to acknowledge this.) So, the funeral ceremony helps us search for meaning in the life and death of the person who died as well as in our own lives and impending deaths. Each funeral we attend serves as a sort of dress rehearsal for our own. When we love someone, and they die, we naturally question the meaning of life and death. Why did this person die? Why now? Why this way? Why does it have to hurt so much? What happens after death? To heal in grief, we have to explore these types of questions if we are ever to become reconciled to our grief. This does not mean we must find definitive answers, only that we need the opportunity to think (and feel) things through.

Funerals are a way in which we as individuals and as a community convey our beliefs and values about life and death. The very fact of a funeral demonstrates that death is important to us. For the living to go on living as fully and as healthily as possible, this is as it should be.

### **Funeral Ceremony Need #6**

Receive ongoing support from others

The Funeral Service is a public vehicle for offering support to others and being supported in grief, both at the time of the funeral ceremony and into the future. Funerals make a social statement that says, "Come support me." Whether they realise it or not, those who choose not to have a funeral are saying, "Don't come support me."

Funerals ceremonies let us physically demonstrate our support, too. Sadly, ours is not a demonstrative society, but at funerals we are "allowed" to embrace, to touch, to comfort. Again, words are inadequate so we non-verbally demonstrate our support. This physical show of support is one of the most important healing aspects of meaningful funeral ceremonies.

Finally, and most simply, a funeral service serves as the central gathering place for mourners. When we care about someone who died or his family members, we go to the funeral if at all possible. Our physical presence is our most important show of support for the living. By attending the funeral, we let everyone else there know that they are not alone in their grief.

### **Sandy Neal**

As my offering today I will share three short stories about funerals I have helped to create and facilitate. I invite you to listen with your hearts as well as your minds. Listen for those moments, those happenings which connect in some way with the things you have already heard from our other presenters or strike a chord with your own stories. To help prepare us for this story telling I invite you to listen to *Firesong* by Anne Powell.

Green of fern refresh us  
Feathers of kereru warm us  
Rocks of Moeraki encircle us  
Waters of Taupo bathe us

Dive of gannet focus us  
Arc of rainbow protect us  
Stars of the Southern Cross guide us

*Firesong*

*Aotearoa Litany by Anne Powell*

The first story took place in a rural town when I was asked to take the funeral of an elderly lady. The large, extended family were deeply shocked and completely grief struck. She was their matriarch, had always been part of their world, head of the family, the one who taught them how to handle life and the world with integrity, grace and wisdom. They were struggling to come to grips with the reality of losing the one who had been the anchor for them as individuals and as a family; their grief was profound.

Their matriarch had been a very private person and left instructions to have a simple funeral without eulogies. The family said they wished to honour her wishes. But as we arranged the funeral service I listened as they told stories which described this jewel of a woman, the place she held in their hearts, the depth of their loss and their inability to even begin to imagine how life might continue without her. I felt very strongly someone needed to give voice to the outpouring of both stories and emotions: and offered to do so on their behalf.

They accepted my offer with the proviso they could still choose not to use what I prepared. I spent some time listening, making notes and then using their words to paint a picture of the person they described, the relationships they shared with her, the joy she had brought into their world and the almost overwhelming sorrow expressed. Finally, I asked them to read what I had prepared and make any comments or alterations they felt necessary.

They discovered that sharing their stories and feelings had been the first step in a healing process. The second step in that healing process came as they heard their own stories, their own words and their own feelings reflected back to them in a very different way. The family members were almost stunned by what they heard and the way those words impacted upon their hearts and minds.

On the day of the funeral the family were astonished to find the large church was filled to overflowing; a reflection of the countless lives this very quiet, gentle lady had influenced in her own special way. She had empowered each person to fulfil their own potential, be the best person they could and, in turn, become their own positive influence in the life of their families and community.

We told those stories, shared the wonder and the tears. We named some of the imperishable gifts she had offered throughout her life, and gave heartfelt thanks for the gift she had been, and would continue to be in the hearts of all those who had been privileged to know her. As we did a quiet, peaceful stillness fell upon all those gathered, a sign of the healing of hearts and minds which would go on into the future.

I offer you a moment of silence to reflect on the thoughts and feelings this story has evoked for you.

The second story comes from a request to take a funeral for a middle-aged woman who had never married. Her large extended family of nephews and nieces, knew her as their spinster aunt who had always cared for them in her own way, but had lived a very solitary life. As I sat with the family it became clear to me some of the distress being experienced by a few of the family members was of a different nature. It took time for them to feel able to trust me but eventually they told a story which changed everything.

They explained that shortly before her death their aunt had introduced them to her son. She had once been very much in love. Unfortunately, she was forbidden to marry the love of her life. When

it was discovered she was pregnant she was sent away to give birth and have the baby adopted before being allowed to come home to her family. This lonely, solitary woman had lived her life grieving for the child she was forced to deny and give to strangers.

Why did these one or two know about this? Because her now adult son had sought out his birth mother. He had experienced a great deal of unhappiness in his early years and had turned to alcohol to help bury his pain and grief. Finally, he had agreed to seek out his birth mother in the hope he could find some sense of healing and peace. Finding and meeting his mother did more than that. There was such an outpouring of love and joy, so many tears and so much forgiveness offered and received, she too, found un hoped for, unexpected, healing and peace. That was when she told these few members of the family her story and waited to see what response she would receive this time round.

As you can imagine, their responses covered the gamut of emotions from disbelief, shock, sadness and grief. They were faced with the judgements and decisions made by their forbears and the terrible toll taken on her life and the life of her son. I'm grateful to be able to tell you these members of her family wrapped her in love and support and asked to meet the young man. Soon afterwards she died.

Those few she had trusted enough to share her story and allow to meet her son were now facing a two-fold challenge. Firstly, preparing their aunt's funeral and secondly, deciding what to do with the new story she had shared with them and the young man who once again waited outside of a family waiting to see whether he would be welcomed in or not.

On the day of the funeral that story was told and all those present were introduced to this new found member of the family. It was a time to acknowledge loss and grief for both the past and the present. However, it was also transformed into a time of discovery, rejoicing and celebration for the gift this special lady had left behind, for both her son and her extended family.

I offer you a moment's silence to reflect.

My final story began when a young woman came to the church office saying she needed to talk to someone. She was very distressed and told me she had lost all hope and wanted to die. I learned she was divorced, had two children and had been in a relationship with a man to whom she had become pregnant. The man told her she must abort the baby or else he would leave her. She confessed that against her own better judgement and desires she had done this. Shortly, thereafter, the man had left her anyway.

Over the weeks and months which followed she came again and again because she had found a safe place to come where she could tell her story and express the terrible gamut of emotions and turmoil which filled her heart and mind, body and soul. As I listened I learned she had always wanted another baby of the opposite gender to the two young children she already had. She believed the baby she had aborted was that longed for child. She still felt pregnant. Her pain, loss and grief were deep and, at times, almost overwhelming. Eventually we found a way forward.

I prepared a special private service for her which was held on the date the baby was expected to have been born. It took place in a small chapel in the presence of her four closest friends. None of her family knew anything of her situation, but these few she had entrusted with her story and they came to support her at her request.

The altar was set in readiness for communion, candles lit, plate, chalice, bread and wine awaiting. We spent a short time in silence as we acknowledged it was time to give birth. We welcomed the baby into our midst and then gave the baby the name chosen by the mother. Following this naming, firstly the mother and then the friends came forward and placed gifts for the baby on the altar. We offered prayers of thanksgiving for the gift of the baby and acknowledged that this tiny

life had changed our lives forever. None of us would ever be the same again. A commitment was made by all present to live lives which honoured the one we had just welcomed.

Finally, we acknowledged the ending of that life, the loss, pain and grief being experienced and the need to offer and receive the grace of God. We commended the baby into God's care and accepted that care for all those involved. As we gathered to share communion we remembered that in God's space and time all people from all places and all times gather with us including those who have died and gone before us. This time of communion and remembrance would now have an added dimension for those participating that day.

That funeral service became a rite of passage for the young woman who walked in off the street needing help. The healing which took place was clearly reflected in the years which followed. By the time I moved to a new job and location she had met and married a very special young man who took joy in the two children he now shared with her. In fact, the whole family were excited as they waited the birth of their next child.

I have told stories today because for me that's what funerals offer us; the opportunity to tell and hear and share and embrace stories which help shape us, our lives and relationships. Funerals are often understood to be **about** the dead, but I believe they are **for** the living however we may understand life and death.

### About Contributors

#### **Major Ian Kilgour, Salvation Army**

Ian, from a Presbyterian background became a Salvation Army Officer balancing his church work with a significant engagement in community services and issues. Establishing programmes in the fields of youth unemployment, community development and emergency housing, the NZ Government employed Ian as an advisor for ten years across these areas. He then became the Inner City Ministry Chaplain for the Auckland Methodist Mission before returning to the Salvation Army to manage their Social Policy & Parliamentary Unit. In retirement he is an associate minister at St Helier's Presbyterian, Auckland.

#### **The Reverend Alistair McBride**

Alistair has served at Scots Presbyterian Church in Hamilton since 1996. Ordained in 1979 he has served in parishes in Napier, Wellington and Picton, and as Ecumenical Chaplain at Victoria University. He graduated Master of Theology in Pastoral Care from Edinburgh University. He has explored grief since his training and written on a post-modern approach to pastoral care, and most recently contributed to a book on Spirituality and Cancer, exploring his late wife, Denise's, journey with breast cancer.

#### **Dr Brian Ensor**

Brian is the newly appointed Medical Director at Hospice Waikato, having shifted up in June (2018) from Wellington. His initial work was in General Practice but for the past 30 years he has worked in hospices in Lower Hutt, North Shore, and Wellington.

Currently he is serving as Clinical Advisor to Hospice NZ. His published research has been on the drugs we use in the last 24 hours of life, and he is enthusiastic about what a doctor can bring to those facing death, so long as there is a multidisciplinary team in the foreground.

#### **Beth Richards**



A qualified funeral director, Beth has worked at Pellows for the past 25 years. Prior to her time at Pellows she was a funeral organist for ten years. Over this time Beth has observed many changes in the funeral industry. Her passion for assisting grieving people remains her focus. Beth was married to David (for 47 years) and recently widowed, and they have two sons and two grandsons. Beth's interests outside of work include horse-riding, gardening and music.

### **K-M Adams**

K-M (short for Kerrie-Maree) Adams is a free-lance voice talent, Funeral and Wedding Celebrant, and MC. She has worked as a radio broadcaster and voice talent for over 20 years in various roles throughout New Zealand including Breakfast Show co-host at BOP FM in Tauranga, afternoon host at ZM in Wellington and as co-host of the Breakfast Show on Classic Hits, MORE FM and The Breeze in Hamilton.

Married with three children aged 5, 8 and 15, K-M has been closely involved in people's lives as a Wedding and Funeral celebrant for the last six years. Most weeks she would do 2-4 funerals, working with all the major funeral homes in the Waikato. K-M has presented a Workshop for Celebrants at the CANZ (Celebrants Association of NZ) development day and has spoken on grief at the Pellow's Remembrance Service for the past three years.

### **The Reverend Sandy Neal**

Sandy is an Anglican Priest whose roles have included Vicar, Ministry Enabler, Chaplain and Spiritual Care Coordinator. She is presently Chaplain at Atawhai Assisi Home and Hospital and Enabler at St George's and St David's in Dinsdale. Her commitment to pastoral ministry led her to train as a supervisor and spiritual director. Her preferred model of ministry is that of 'Midwife'.

## **Caring for the spirit: lessons from working with the dying**

<https://www.mja.com.au/journal/2003/179/6/caring-spirit-lessons-working-dying>

Bruce D Rumbold

Med J Aust 2003; 179 (6 Suppl): S11. || doi: 10.5694/j.1326-5377.2003.tb05568.x

Published online: 2003-09-15

### **Abstract**

- Spiritual care is integral to palliative care, and palliative care experience in offering spiritual care can be a resource for the emerging healthcare interest in spirituality.
- Spirituality is best understood in terms of the web of relationships that gives coherence to our lives, uniquely identifying each person.
- In palliative care, responsibility for spiritual care is shared by the whole team, with leadership given by specialist practitioners such as pastoral care workers. The palliative care approach to spiritual care may, however, be transferred to other contexts and to individual practice.

Spiritual care encourages and supports people in a quest for meaning and personal autonomy. It is offered, not imposed.

IN THE 1970s, the hospice movement, from which contemporary palliative care has emerged, established a model of care for dying people that encompassed physical, psychological, social and spiritual dimensions of need. Over the past 30 years, hospice and palliative care services have generated a rich store of accounts about the ways in which people face death.<sup>1</sup> These make it plain that the imminence of death, together with the changed circumstances associated with illness,

cause many people to reflect on questions such as: Who do I belong to? What's the purpose of my life? What can I hope for?

Traditionally, questions like these received religious answers, and hospice care practitioners regarded attending to these questions as spiritual care. To do so, they drew at first upon religious resources, but soon began to develop a broader perspective in which spirituality was understood as “ultimate meaning”. Concepts enunciated by Cicely Saunders — “openness, mind together with heart, and a deep concern for the freedom of each individual to make his or her own journey towards their ultimate goals”<sup>2</sup> — were considered fundamental to hospice practice. The role of practitioners was to be companions on this journey, responding to the dying person's spiritual quest rather than imposing their own views. They observed that people became aware of spiritual need in various ways: through trying to cope with their changed physical, emotional or social environment; through seeking to redefine their personal identity in changed circumstances; or as a result of their religious beliefs and practices.

Kellehear rightly points out that a multidimensional model incorporating all three of these aspects (situational, moral/biographical and religious) is essential.<sup>3</sup> Spirituality is inseparable from everyday life and experience. It denotes perceptions, insights and beliefs that reconnect facets of personal experience fragmented first by life in modern materialist society, then by a healthcare system that delivers multiple services through a variety of practitioners, with little attention to the overall impact on the recipient. Spirituality, as palliative care practitioners understand it, is often expressed in everyday language that may not be recognised as “spiritual” by people whose ears are attuned principally to religious language or who regard spirituality as something separate from ordinary experience.<sup>4,5,6</sup>

### Describing spirituality

Spirituality may be described as the web of relationships that gives coherence to our lives. Religious belief may or may not be part of that web. Often we only become aware of strands in the web when they are stretched or broken, as happens with a life-changing event like a diagnosis of serious illness in ourselves or in someone we love.

Lartey describes this web of relationships as “levels of a system”.<sup>7</sup> Spirituality, he says, involves relationships with places and things, with ourselves, with significant others, with groups and communities, with transcendence. For each of us, these relationships form a unique pattern, and each of us needs that pattern to be largely intact in order to feel secure, or whole. Some of us feel most whole in particular places or when surrounded by particular things or by people we love; some of us feel whole when, through prayer, ritual or silent waiting, we find ourselves close to God. Our web of key relationships defines who we are, and when those relationships are disrupted, we feel vulnerable. Klass has suggested that “a good way to begin thinking about spiritual life . . . is to look for those moments when we feel most deeply connected to our world, when we feel least isolated inside our usual ego boundaries. We feel a part of something larger than ourselves, and the rest of the world makes sense.”<sup>8</sup>

### Spirituality and religion: a continuing debate

In the palliative care context, spiritual care supports people in searching for meaning in their dying. Survivors of life-threatening illness also indicate the need to attend to spiritual issues in order to resume everyday life. Connections between health, religion, and spirituality have received increasing attention in recent years, although comparison between studies is complicated by conceptual and terminological differences. A succinct review is given in recent paper by Peach.<sup>9</sup> (The subsequent exchanges between Peach and Koenig demonstrate these complications

and the potential for misunderstanding that can occur when the terms “religion” and “spirituality” are used more or less interchangeably.[10,11,12](#))

Many people today describe themselves as spiritual but not religious: they seek spiritual experiences, but neither interpret nor express these through conventional religion. Conceptually, the relationship between religion and spirituality is complex. Religious beliefs and practices focus more upon the sacred; contemporary spirituality attends more to the self. Religion points to Spirit, of which the human spirit is a reflection; contemporary spirituality attends to and expresses the human spirit. Some contemporary spiritualities draw upon the resources of several religions;[13](#) some religious spiritualities today adopt the form of other contemporary spiritualities in the authority given to subjective experience.

A religion-based understanding of spirituality — spirituality as beliefs about the sacred — tends to be more acceptable in healthcare contexts because it provides definitional clarity that assists the division of professional responsibilities. However, many patients do not observe this conceptual neatness, applying the term “spiritual” to core values, meanings and practices that integrate their experience, often with only tenuous connection to ideas of transcendence. This popular usage makes defining spirituality in terms of the content of belief virtually impossible; but behind the variety of content is a common process. Spirituality involves a quest for meaning — a meaning that is personal.[14,15](#) Individuals embrace spirituality to affirm themselves in the face of the “expert” knowledge they experience as taking over their lives. Contemporary spirituality resists the expert authority of both tradition (religion) and modernity (medicine).

Of course, many of today’s older patients are religious in a traditional sense, while others will not countenance any talk about spirituality. But the proportion of those who understand spirituality as a personal quest is growing. An important implication is that, to offer spiritual care, healthcare practitioners must engage with patients as companions on a quest. An “expert” stance will not be effective — practitioners should begin not with formal definitions but with the lived experience of the patient.[16](#)

## Spiritual care

In palliative care, providing spiritual care is a whole-team responsibility. All are involved in attending to the connections and disconnections in each patient’s web of relationships. Some of these become apparent in an admission interview; others emerge as patients develop trust in team members and share stories of their lives, their current concerns, their hopes and fears concerning the future. Over time, a picture of the web emerges. It is essential that spirituality be monitored over the course of the illness, as issues arise at different points for different people. Some already have answers to existential questions before illness disrupts their lives; some only begin to reflect after diagnosis; some defer them permanently.

For some patients it is enough to have their spiritual needs and resources acknowledged, implicitly or explicitly, by the team. Others will want to examine the significance of what has emerged. Working with an individual to explore the meaning of these connections and disconnections — as compared with observing them — is best done by team members with expertise in processes of self-understanding, changing perceptions, and spiritual development: psychologists, social workers, and pastoral care workers. Referral may also be appropriate, particularly for those who would appreciate care from an authorised religious practitioner. The overall spiritual care strategy will involve the whole team.

The strength of a team approach is that the variety of relationships available to the patient more readily elicits the diverse strands of the web. However, spiritual care offered by individual practitioners follows a similar approach. It begins with attention, offers companionship in exploring issues that arise, encourages a quest for meaning, and continues to support the relationships that

give life. Strategies for care will address physical, psychological, social and spiritual aspects of a person's life, and may involve intervention to change his or her circumstances, assistance in revising a sense of self, or support to re-examine fundamental beliefs.

Finally, spiritual care is to be offered, not imposed. Clinical practitioners are often in an ideal position to offer spiritual care, precisely because they are involved in the experiences that disrupt patients' lives. Practitioners' attention to spiritual concerns, and their capacity to legitimate spiritual quest, can be enormously powerful. But there is an associated danger that the prescriptive approaches of clinical treatment can be extended to spiritual interventions. If so, it is more likely that these will be experienced not as care but as an intrusion. It is a fundamental requirement of spiritual care that we respect the way people go about looking for answers, for at this point what matters is not the content so much as the quest itself.

## The Suffering Patient: Dr Megan Best, Hammond Care and University of Sydney

*Hospice NZ, Palliative Care Lecture Series 2016 – December 1<sup>st</sup> 2016*

Suffering has a context. The same excruciating abdominal pain may mean suffering to one and to another a temporary pain but mostly joy for the baby on the way.

Sometimes medical interventions become the source of suffering.

Suffering is not a medical problem, it is existential. It is about the meaning a person attaches to an experience.

Victor Frankl:

*In some ways suffering ceases to be suffering at the moment it finds a meaning, such as the meaning of a sacrifice*

Dame Cicely Saunders (Founder of Hospice) defined the concept of total pain as the suffering that encompasses all of a person's physical, psychological, social, spiritual, and practical struggles.

Eric Cassell. Suffering is experienced by persons, not merely by bodies, and has its source in challenges that threaten the intactness of the person as a complex social and psychological entity. Suffering can include physical pain but is by no means limited to it. The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself.

Suffering is defined as "an encompassing, dynamic, individual phenomenon characterised by the experience of alienation, helplessness, hopelessness and meaningless in the sufferer which is difficult for them to articulate. It is multi-dimensional and usually incorporates an undesirable, negative quality (Best et al)

Loss is intrinsic to the cancer journey

Aunt Matilda's cake – Scientific analysis can reveal: calories, proteins, fats, elements and their bonding, fundamental particles, equations to describe the motion of the particles. But what's its purpose? The only way you can work that out is to ask Aunt Matilda.

Don't assume you know the main source of suffering. Sometimes it will surprise you what is hardest for someone about their situation.

1. Treatment – facilitating the articulation of spiritual suffering and promoting recovery of meaning.
2. Prevention – by supporting the patient’s spiritual well-being in healthcare.

#### Consensus definition

Puchalski “Spirituality is the aspect of humanity that refers to the way individuals seek and express meaning and purpose and the way they experience their connectedness to the moment, to self, to others, to nature and to the significant or sacred.”

Spirituality is relationship:

- with self(inner strength)
- With significant others
- with places and things (eg nature, music, art)
- with transcendence or that which is ‘beyond’ (eg mystery of the universe, God, fate, ancestors)

Sickness: relationships disrupted. This explains why severe illness brings on existential questions. Spirituality is connected to Quality of Life.

Healing is possible even when someone is not physically well.

The danger of always linking spirituality to end of life is ignoring it at other times.

#### Beneficial Impact of Spirituality/Religion

Aspect of Health	Highest level of Evidence
Stress reduction	Kraus and Van Tran (1989), Leserman et al (1989), Williams et al (1991)
Relief of depression	Cartner et al (1981), Koenig et al (1998)
Recovery from illness	Levin 1996
Prevention of substance abuse	Larson (1980), Koenig (2001), Gorsuch (1995), Carroll (1993)
Prevention of suicide	Gonda et al (2007)
Prevention of heart disease and hypertension	Carroll (1993), Fraser and Sharlik (1997), Levin and Vanderpool (1987)
Relief of pain	Kabar-Zinn et al (1985)
Adjustment to disability	Idler and Kasl (1997)
Recovery of cardiac surgery	Oxman et al (1995)
Longevity	Hummer et al (1999), Clark et al (1999)
Reduced incidence and longer survival with cancer	Kune et al (1993)
Improved palliative care outcomes	Duggleby et al (2007)
Counselling outcomes	Hassad (1999)
Coping with illness	Hassed (2008), D’Souza (2007), Williams and Sternthal (2007), Herbert et al (2001), Eckersley ( 2007), Selway and Ashman (1998)

All staff need to recognise spiritual distress (doctors, nurses, allied staff, social workers, cleaners psychologists) but the chaplain is the specialist.

Rituals and customs can help.

Patients want staff to support their beliefs, to ask, to refer, to understand them as an individual, a real person. Sometimes that may mean allowing more time with family, relaxing visiting hours.

Burdens of Spiritual Care:

- difficult conversations
- high level doctor discomfort
- lack of training
- advanced communication skills needed
- Burnout risk

Advanced communication skills can be learnt.

What is needed is:

- a high awareness of one's own spirituality, knowing yourself so you don't become distracted/defensive.
- Time to bring up spiritual care, it doesn't take a lot of time actually when you know how

Are you at peace? (Steinhauser et al 2006)

Best (2015: Creating a safe space: A qualitative inquiry into the way doctors discuss spirituality):

1. What is important to you for me to care for you?
2. What matters at this time when you're really, really crook?
3. What's vital for me to know that helps me ensure that you're comfortable and you're at peace?

Learning from the Experts

- Developing the self
- Developing one's attitude
- Approaching the patient

Be comfortable with one's own mortality - when we show self, the patient feels safe

"In any spiritual encounter, you're sort of being a companion and being there whatever it looks like, and so not – I don't need to fix everything; it's about being with, and what's helped me – I'm not saying that I get it right all the time by any means, but I think what helped me is my belief in it, but also my willingness to be vulnerable and to sit in that space and not need to have to solve or fix, and being able to live with the uncertainty and not having all the answers. I think that's not akin to the traditional necessarily, it's more of a healer model than a fixed medical model. So for me, it's about being truly myself in that space and allowing the patient to be truly themselves. It's a very deep thing really."

"Well, I think of someone who is really struggling, for example with nausea and vague pain and...we couldn't really get control of those symptoms really well,...I guess with experience, you get a hunch that you're missing something, you know, you haven't got the full picture here and then actually going and sitting down, closing the door, just a one-on-one discussion with the patient. Asking them about how they think they're going, you know, what's happening for them, what they are most afraid of, if that's an issue, and just teasing out some of those non-physical stuff can also help

you find out that the person is actually petrified of dying like their great aunt did in some dramatic end of life episode. You know, or they're afraid or they haven't made amends with their family or they've got those sorts of things going on, you can then get an insight into what might be impinging on those difficult, difficult to control symptoms."

"Listen. Listen with the head but listen with the heart. Allow silence. Don't feel that you have to have all the answers, and realise that this isn't about you and isn't about me, I'll be telling myself, it's about the patient. In other words, just to keep checking in with their body language and what they're saying to see if it is actually therapeutic and helpful. It's certainly not a checklist approach. But it's not always – if it doesn't seem easy to me, it doesn't necessarily mean it's bad for the patient, but by far, probably one of the most important things is to learn not to assume anything. I have looked after people that are in either religious orders or vicars who have lost their faith for example but haven't necessarily let that be known to other people. So just assuming for example, if it's a vicar with a title, if you just assumed things you might not really be able to get to the nub of what's troubling them."

## The Dying Role

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and VIRGINIA E. RICHARDSON, Ph.D.<sup>3</sup>

### ABSTRACT

**Background:** Roles are relevant during the last stage of the life cycle, as at any other stage. Awareness and an understanding of the dying role have the capacity to guide the process. Lack thereof can impede good deaths and may have been in part responsible for the intense and often futile interventions provided to many dying patients in the past.

**Objective and design:** We describe relevant aspects of role theory and recent scholarship and then examine the dying role, describing three key elements: the practical element, which involves concrete tasks of preparation; the relational element, which involves engaging with others; and the personal element, which involves tasks that foster personal growth and finishing one's life story. We also identify some barriers to and misuses of the dying role that appear to limit productive engagement with it, and offer suggestions for how clinicians can assist patients with the dying role.

**Results and conclusion:** The described elements of the dying role, and appreciation of how to avoid barriers and facilitate its implementation, can help patients access the unique quality of life that can occur near the end of life.

### INTRODUCTION

A few days before she dies, a hospice patient says, "I don't know what to do; I've never died before." Her daughter says, "Me neither; I've never been with anyone dying before."

PEOPLE WHO HAVE TERMINAL ILLNESSES and their families and community often lack experience with death, which today occurs largely in institutions, and so they engage in the dying process with a sense of uncertainty that goes beyond anticipation of death or loss. Literary, performing, and visual arts assume and portray how people engage in the process of dying, and thereby portray the roles of dying people and those around them. Similarly, social scientists have conceptu-

alized death and dying in many works.<sup>4-11</sup> Yet, in recent decades, society at large has been reluctant to acknowledge matters of death and dying. Dying is inherently difficult and having little experience related to any role that helps a person to navigate the dying process presents a needless additional handicap.<sup>12</sup> Furthermore, if for lack of a dying role, terminally ill people remain in a sick role, this may be responsible for futile use of curative interventions and perhaps for some needless expenditures.<sup>13-15</sup> We are motivated to describe roles related to dying by the expectation that awareness of and research on the topic will foster better therapeutic interventions that promote a good dying process. We focus here on the role of the dying person, organizing the paper into three parts. First, we review previous writings on the dying role, sociological perspec-

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tives on death and dying, and role theories. Of note, we acknowledge that there is debate about whether there is one role or many, a rigid or fluid role, or a spectrum of roles for dying. We do not take a definitive position on this, because it is awareness of rather than consensus on the matter that will foster the progress we seek. For simplicity, we use the singular form, "dying role," and we use "subrole" rather than "component of the role" to designate this complex set of options. Second, we describe a model of the dying role by articulating some of the key practical, relational, and personal components that may comprise it. Third, we identify barriers to and potential misuses of the dying role. Finally, we comment on how enhanced attention to the dying role may assist clinicians in providing appropriate, quality care for the dying.

## BACKGROUND

Roles generally facilitate how people negotiate life's tasks.<sup>16</sup> They offer "maps" that guide people through their interactions and evaluations of themselves.<sup>17</sup> The dying role is a final role. Although they are constructed within a social context, roles appear to have an inherent nature. People do not need to study or articulate much to have an instinctive understanding of and strong feelings about roles, although some roles are better supported by the culture than others. Key roles should have a describable structure or set of inherent features that allows a description of an underlying model or template. In everyday life, such templates apply fluidly, in combinations with other roles and in varied circumstances. This combination of inherent nature, social construction, and individual and collective application is as true for the dying role as for others.<sup>8,18,19</sup>

Defining "role" is complex. Biddle<sup>20</sup> defines roles as "behaviors characteristic of persons in a context." Ferraro<sup>16</sup> maintains that "[roles] provide normative guidance to a person [and] help shape expectations of the life course as roles are added and relinquished." Roles also guide others in how to respond. Similarly, when people fail to accomplish role behaviors, they may experience social disapproval and feelings of insecurity. Shaw and Constanzo<sup>21</sup> as well as Heiss<sup>22</sup> also describe roles in terms of functions and expectations, noting that although expectations originate

from multiple sources (including society), it is the individual's own expectations that most directly influence his or her behavior. Heiss refers to a role "repertoire" as the constellation of all the role and sub-roles of a particular person. Subroles denote different expected functions and behavior for different settings. Others emphasize the interpretation and negotiation of roles.<sup>23,24</sup> In keeping with this thinking, Lopata<sup>25</sup> argues that role expectations are negotiated between an individual and his or her social circle.

Ferraro<sup>16</sup> describes how role theorists have shifted from a problem-focused emphasis to a more dynamic view of roles that incorporates a life course perspective. This view takes into account the timing, social supports, previous coping styles, culture, history, and antecedents and consequences involved with role transitions. Today role theorists place greater emphasis on people's resilience and capacity to compensate for losses, including later in life, than they did in their earlier writings. For example, Baltes and Baltes<sup>26</sup> argue that contrary to previous stereotypes and assumptions, older adults are resourceful, adapt well to change and, most importantly, evidence tremendous variability in their adjustment to roles and role transitions. Similarly, in her study of caregivers, Moen<sup>27</sup> found that the timing, duration and contextual features of a role were important.

Psychologists also emphasize life stages. Erikson's well-known stages of psychosocial development, for instance, include the stage of maturity late in life, in which people strive to achieve ego-integrity as they review their lives, make sense of their experiences and pass on their learning.<sup>28</sup> Recently Knight and Emanuel,<sup>29,30</sup> in keeping with Byock, have described how dying people can also achieve life cycle-specific adaptation and creative growth. These stages can be understood as contributors to life cycle-related roles.

Parsons<sup>4</sup> postulated a sick role, which he viewed as a deviant but necessary role, that preserved the stability of social organizations. Parsons also suggested that the sick role offered people certain rights, such as time off from their daily responsibilities and from other forms of accountability especially with regard to their medical conditions. Parsons perceived the sick role as a temporary role from which people would exit once they recovered from their illnesses. Several scholars now argue for a dying role that is distinct from a sick role that takes into account peo-

ple suffering from illnesses from which they will never recover.<sup>31-33</sup> Parker-Oliver,<sup>33</sup> who cogently critiqued the sick role, proposed a dying role that she asserts emerges when physicians, the “gatekeepers” to entry into a dying role, diagnose a person with a chronic or terminal illness. According to Parker-Oliver,<sup>33</sup> when physicians refer people to hospices, patients officially enter the dying role because in hospices the focus is on comfort rather than cure. Seale<sup>8</sup> argues that protracted deaths from cancer and other chronic illnesses, along with inevitable awareness of dying during these situations, have contributed to the recreation of a modern dying role. Field<sup>19</sup> similarly argues that a “modern role of dying” is emerging and will become increasingly important as people die from chronic illnesses such as cancer. Seale<sup>34</sup> also notes that compared to previous decades, people now can participate more actively with death through hospice care, a return to enactment of death rituals, and relevant television and news coverage. Glaser and Strauss<sup>5,35</sup> documented the benefits of death awareness and described how people often reach closure before death by writing letters, planning legacies, and reconciling with others.

Awareness of the dying role can contribute to the way practitioners care for the dying. We illustrate this point with the case of Mr. S. This is a true case contributed by the first author, deidentified for purposes of patient confidentiality.

Mr. S. had given up fighting his disease, had become deeply despondent and felt that it was time to “be a portrait on the wall.” When it was suggested to him that he had important work to do by showing his grandson “how a real man dies,” his mood lifted and he set about passing on family stories and wisdom to his grandson and tried to make sure all concerned had what he could offer them before he died. When this elderly man had no sense of what role was left for him, he was downhearted and inclined to

give up; after he had expectations to aspire to, he became purposeful about engaging the role of dying well. Entry into the role, however, was prompted by and negotiated with those around him; it required adaptation and integration into his life course roles of parent and grandparent.

### A MODEL OF THE DYING ROLE

In her seminal work on care for the dying, pioneer of the modern hospice movement, Saunders<sup>36</sup> identified the four major domains of a person’s experience near the end of life as: physical, mental, social, and spiritual. This concept has since been validated in the broad sense that others have also found that a person’s dying experience comprises all major aspects of a person’s life.<sup>14,37-41</sup> The domains appear to influence one another.<sup>42,43</sup> We therefore describe the dying role as comprising similarly comprehensive and interactive yet distinguishable domains: practical (physical and logistical), relational (social), and personal (psychological and existential) domains. These domains are depicted in Table 1, and are further illustrated below.

In keeping with role theory and recent scholarship on the dying role, and in that the dying role is taken on from within the context of historical, social and individual influences, we see the functions and expectations in each domain as having the capacity to vary; we also see that experience in each domain might have significance for and influence on each other domain, so in this sense they are fluid.<sup>42,43</sup> The present model describes features of the dying role in contemporary America.

#### *Practical features of the dying role*

By “practical” we mean to denote both physical-medical and logistical features. Medical care was defined during the course of the mid-twen-

TABLE 1. KEY FEATURES OF THE DYING ROLE

<i>Practical tasks</i>	<i>Relational tasks</i>	<i>Personal tasks</i>
Financial legacy	Coexistence with other roles	Adjustment to loss
End-of-life planning	Teaching the dying role	Reaching closure
Caring for dependents	Passing the mantle	Existential tasks
Last good-byes	Giving permission	Final growth phase
	Placing a legacy capstone	Last rites of passage

tieth century by the assumption that the goal was to cure or at least prolong life. For much of modern medicine, that is still the case. However, for the person who has entered the dying role, the assumption is that the goal of care is quality of life within the constraints of inevitable disease progression and death. Since the rise of the hospice and palliative care movement in recent decades, physical care for the dying focuses on symptom control so that physical limitations and suffering are minimized and other aspects of the dying role can proceed. Interventions that are aimed at cure are no longer relevant. Both the patient and the patient's close circle of family and friends as well as the professional care team are encouraged by the expectations of the dying role to select appropriate goals of physical care. This usually has considerable practical manifestations, such as moving the site of care to home, and/or selecting medical interventions that have minimal invasiveness or associated discomfort.

Logistical features of the dying role are characterized by the person's desire to make arrangements for his or her expected demise. The person who enters the dying role usually wants to make sure that his or her estate or will is in order, including any material gifts and financial legacy. The person in the dying role will likely also make practical arrangements for care of any dependents. Roughly half of people with terminal illnesses have participated in this kind of estate planning.<sup>44</sup>

A related task involves creation of plans for medical care in case of decisional incapacity. A person who expects to die soon often understands that the predeath phases may entail an inability to make or communicate decisions. He or she therefore may try to assist those who will provide care by giving advance directives for such circumstances by discussing the matter, writing a letter or completing an advance directive for healthcare (living will). Some also prepare for their postdeath memorial service and make decisions about cremation, burial options, and funerals and memorial services.

#### *Relational features of the dying role*

Dying roles coexist with other characteristic roles that relate to the dying role. The person in the dying role relates, sometimes intensely, to those in related roles. Other roles include the caregiver role, the marital role, the parental role,

and the child role, as well as, eventually, the bereavement role.

One component of a subrole for the dying role is related to that of the wise elder who provides guidance and teaching. The teaching is, however, specific to the journey of dying and is often directed to those in related roles. One dying person who took this subrole seriously left her teaching on a website to maximize its reach.<sup>45</sup> After discovering that she had serious, aggressive cancer, Kit went to her meditation group where, in addition to meditating, she taught other members of the group about her understandings on dying. One member commented:

This group and the things we're talking about are really helpful to me and I've learned a lot from the work we're doing here and from your attitude. I mean, just the idea of what you said—that you see yourself now on the journey of dying—that's a very positive way to look at it. I think all this has helped me to be a little more comfortable with my own mortality.

Another subrole has to do with "passing the mantle." Often in a communication that involves symbolic acts, the person in the dying role passes other key roles that he or she has held to another person. For instance, a mother for whom cooking has symbolized nurturance and the parenting role may give her recipe collection to her children or other family members. In some cultures, people who expect to die soon create an ethical will or statement of values for their successors.<sup>46</sup> In many cultures, it is traditional for a dying parent or leader to bless his or her children or community members. Perhaps this blessing will entail identification of an heir apparent, or perhaps it will set out a projected direction to pursue or describe a person's situation in the grander scheme of life. Blessings can be a routine part of many cultures; the unique features of a blessing by a person in the dying role is that he or she expects it to be the last and most permanent blessing that endures beyond his or her life, and the recipient usually expects the same.

A related subrole has to do with permission- or instruction-giving. People who are dying often realize that those who are left behind should and must continue living. Parents, in particular, characteristically want their children to know that it is okay and important to continue living fully af-

ter they are gone. They want their children to be happy and fulfilled. Pat's assumption of this subrole illustrates this:

Pat's husband was diagnosed with leukemia while they were in the prime of their lives, and still had four young children at home. In his final days as he lay in his hospital bed, he told his wife that it was okay to move on. He gave her permission to marry again, told her that she was an excellent mother, and would need to be there for the children.<sup>47</sup>

Reciprocal subroles of permission giver exist for the caregiver, who may tell a dying person that it is okay to die and assure them that they will be all right after the dying person is gone.

Yet another subrole is closely related to personal aspects of the dying role and it has to do with finalizing a life story or legacy. People often devote much of their life's efforts to making an impact that will last beyond their death, whether through the existence of their children, people that they have influenced, the social institutions where they have worked, or items they have produced (such as books, art work or craft items, things or innovations, policies or laws). People often have a compelling need to "write the last chapter" of their life work; they may need to finish a project, or receive a public acknowledgement or participate in a meaningful life cycle event in a friend's or family member's life. In the last instance, this is sometimes a birth or graduation or wedding. This finalization of a life story or legacy often has great impact on the person in the dying role, who may seem to be "ready to die" when that job is done, and who may equally seem to hang on to life beyond all expectations and with inspiring tenacity if the event has occurred.

The relational components of the dying role include characteristic patterns of negotiated transitions, especially in relationship to the coexisting roles. For instance, when the sick person transitions from the sick to the dying role, the patient or family members who are not emotionally ready for the transition may be resistant and conflict may occur with those who are ready to start enacting the role or coexisting roles that imply acceptance of death. Even for those who are ready, negotiations tend to occur over who takes which aspects of the caregiver roles now. For instance, the wife of a sick man may "move over" to allow

more presence from the son who is a pastor and has had spiritual leadership within the family or for another sibling who needs to settle issues before it is too late. However, such a transition may not be easy for yet another sibling who, say, also needs a meaningful role and cannot find one. Negotiations also often pick up around this time over who is in line to take which of the social roles that may be open when the dying person is gone.

The relational features of the dying role often entail demanding tasks. The person who is able to enter the dying role before illness interrupts their capacity to relate is able to accomplish these relationship tasks with the advantage of time and awareness.

#### *Personal features of the dying role*

Finally, the personal components of the dying role contribute to a person's self-definition (i.e., his or her identity). That is, the dying role carries with it a kind of awareness of its modification to self. It facilitates an understanding of important experiences about who the person is and how dying affects or informs that identity; it does so within a framework that provides prescriptive guidance, informing expectations, social norms, and a sense of social acceptance if the role is fulfilled. Entry into the dying role is often accompanied by profoundly meaningful personal events that are transforming. People with life-shortening illnesses typically face a series of deep losses that begins with the loss of their future and progresses to include physical, social, and sometimes cognitive losses. The dying role carries expectations that the dying person will have awareness of dying-related losses and will engage in adjustments to those losses. With each loss and each adaptation to that loss, the meaning of what has been lost and its place in the person's identity can be integrated.<sup>29</sup>

Most widely recognized, perhaps, is the task or job of reaching some kind of closure or settling with people with whom the dying person has meaningful relationships or with people with whom they have unfinished business. One instance of this is provided by a woman named Suzanne.<sup>48</sup>

After being told that she only had 6 weeks to live, Suzanne began to reach out to family members with whom she had difficult relationships. She called all of her children and grandchildren to make any necessary apolo-

gies, offer forgiveness, and say her good-byes. In the last weeks of her life, she reached out to siblings. Their abusive upbringing had left everyone embittered, and they had lost all contact. She gathered them all around her to talk and reconcile. Suzanne was surrounded with family on her final day. Her illness had brought them all together.

Possibly the tendency to engage in a review of one's life when one expects it to end shortly prompts participants to settle outstanding issues that come up in the review. Ioline's story illustrates such a process.<sup>49</sup> A 36-year-old musician and former prostitute with acquired immune deficiency syndrome (AIDS), Ioline shares how she reviewed her life.

It's funny—when you are dying you think about incidents in your life in a different way. [ . . . ] Since I learned I have AIDS [ . . . ] I've thought about my life [ . . . ] Just facing your mortality triggers something, and it causes you to start thinking in a different way.

Dying is, by definition, an existential matter. On a personal level, entering the dying role necessitates engagement with the existential questions of mortality. For many people, even for those who hold steadfast beliefs and use well-established frameworks of understanding, this means revisiting assumptions. For many this means bolstering or creating a framework that feels adequate to the challenge of dying. For Kit (also quoted above), a woman dying of cancer, searching for a way to conceptualize what it would mean to no longer exist in her present state was important.

The Eastern beliefs I'm studying say I will find my place in the universe and that I will continue to be part of life in some way. Judaism tells me I will rest in proximity to God. I don't know exactly what these ideas mean but I do want to believe them with all my heart. And some days I do. Some days, when I'm together, I can almost feel a kind of excitement to think these things might be true.

Perhaps as a result of these two spheres of engagement, namely, reaching closure and existen-

tial awareness, people in the dying role often seem to enter a characteristic final growth phase.<sup>30</sup> Even when people are close to death, personal growth may continue. The story of Douglas illustrates such growth:

Douglas was an ex-army sergeant [who] would yell at his doctor [ . . . ], belittle his wife [ . . . ], and call his son lazy [ . . . ] Then Douglas began to change [ . . . ] He apologized to his doctor for all the angry words [ . . . ] Douglas was able to return home, where [h]e and his wife began to share their favorite memories of their life together. He got along with his son and repaired his relationship with his estranged father, saying it was because he had "grown up" while he was in the hospital.<sup>30</sup>

Depending on a person's tradition, there may be a last job to accomplish—often by the dying person—namely, to make a last statement of commitment. For some, this involves taking the last rites or saying the last prayers assigned by their tradition for the dying. These last acts can serve to connect the survivors to the person who is dying in that they may feel affirmed in a commitment to their common values.

## COMMON BARRIERS TO THE DYING ROLE

Social acceptance of a role usually entails the creation of norms and institutionalized expectations that facilitate the functions of that role. Since roles are socially constructed and individually negotiated as well as inherently intuited, the norms associated with it are also negotiated. In the same way that social acceptance of a role entails facilitation of its enactment, social disinclination fosters barriers to the role. Here we provide examples of barriers that are still prevalent and can interfere with people's successful participation in a dying role (Table 2).

### *Lack of death awareness*

Death awareness is an essential condition for entry into the dying role, according to Seale.<sup>8</sup> Some diseases, such as cancer, are more amenable to the experience of a dying role than others. When people die suddenly and unexpectedly,

TABLE 2. BARRIERS TO ENTERING THE DYING ROLE

Lack of death awareness
Cultural barriers
Lack of access to hospice or palliative care
Poor symptom control
Inadequate knowledge
Situational barriers

death awareness is typically impossible. Dementia may also hinder death awareness and entry into the dying role. Health professionals, family members, and dying persons who do not acknowledge death may hinder death awareness and futile interventions may be tried. Cultural factors also can affect the dying role. For example, in some countries (such as Japan) health professionals and family members are more inclined to avoid open discussions about dying.<sup>8,50</sup>

#### *Lack of access to hospice or palliative care*

People dying in a setting that makes little accommodation for those who are doing the work of dying, perhaps an intensive care unit or busy hospital ward or perhaps in the case of a disenfranchised person with sparse support relationships, may have a difficult time entering and benefiting from that role.<sup>51</sup> Care that facilitates the role is characteristically provided by hospice or palliative care team. The absence of those services can present a barrier to accessing the dying role.<sup>52</sup> To ensure access, hospice and palliative care services need to accommodate the full socio-demographic and illness diversity of the terminally ill population so that none feel disenfranchised.<sup>53,54</sup>

#### *Poor symptom control, lack of whole-person care*

A related common barrier is poor symptom control. Physical suffering consumes the focus of both the patient and the family so that the work of the dying role may be difficult to accomplish. Poor symptom control can lead a person to seek an accelerated dying process, and thus lose the chance for all the benefits of the dying role. Consider Ms. Wein, a 53-year-old woman who was dying of ovarian cancer.<sup>55</sup>

Ms. Wein commented, "My symptoms had taken over my life. I wanted to die. Death had to be better than feeling sick." After Ms. Wein was moved to the care of hospice, she

found that she was finally able to sleep and rest. Medications were able to control her nausea, vomiting, and depression. Finally she was able to have discussions with her family and friends, and was able to share what she wanted to do with her remaining days.

Symptom control involves more than the physical dimension. Lack of attention to the manifestations of illness in the psychological, social and spiritual domains diminishes the person and tacitly supports non-acknowledgment of the dying role and all that it entails.<sup>56</sup>

#### *Inadequate knowledge, skills*

Ignorance on the part of the professional caregiver or family members of what is needed for a successful dying role is yet another barrier. Knowledge of the relevant culture may be inadequate.<sup>51</sup> Most cultures have rituals, explanatory models, sayings, writings, and community expectations that can be a great help to those who subscribe to them. Given the existential nature of death, cultural competence in this situation is inextricably linked with something that might be called spiritual competence. Each person, whether from a humanist, monotheistic, eastern, or any other tradition, comes with a set of assumptions and will likely seek or need spiritual resources during this time. Cultural and spiritual competence, as it pertains to dying, within the care team is important in facilitating these features in the dying role.

Part of this competence requires the professional's own existential maturity. Prigerson<sup>57</sup> found that providers who "accept death" are much more likely to disclose a patient's terminal diagnosis. This disclosure is vital to a patient who is attempting to acknowledge his or her own death and it also increases the likelihood that the patient will receive palliative care. Clinical skills in helping the patient and family move from the sick to the dying role by helping them to select goals for care that are appropriate to their prognosis are also essential.

## MISUSES OF THE DYING ROLE

Most roles have the potential for misuse. For instance, a person in the role of parent can mis-

use that socially sanctioned position to engage in unacceptable behaviors, as can a teacher, and so on. The dying role also has hazards.

One hazard is the imposition of a normative “good death” on all dying patients. Just as for any role in life there is not one rigid mold that is satisfactory for all, there is not one for dying, and stereotypes should be resisted.<sup>57</sup> For instance, most need to reach resolution in relationships, but some differences remain of ultimate importance to people and they may need to die with those differences intact. In general, although a template or model of the dying role seems to be relevant to all, the engagement of that role is widely divergent.

Additional hazards of the dying role may entail timing, manipulation, or devaluation. A person can enter the dying role prematurely, or be persuaded to enter it prematurely. A person in the dying role can exploit the privileges of the role, leaving those around him or her with a legacy of guilt or overburdening them with unnecessary work. A dying person can be needlessly stripped of other roles and may be devalued personally or by society. Another potential misuse involves the inappropriate imposition of obligations of the dying role; people should not be made to feel overly obliged to engage in the above mentioned tasks of dying in a fashion that feels in-authentic to them.

An important problem might be perceived failure in the dying role. The dying person, the caregiver, or others in role-relation to the dying person may not perform the tasks or conform to the behaviors associated with the role. Among role-related failures, this one is marked by the fact that it is impossible to reverse and, for this reason, it is especially important to be flexible about what constitutes acceptability. Perceived failure in the role may occur if there is a disparity in expectations among the parties or if there is such discomfort with a role that it causes its own type of suffering. Ideally, a better understanding of the nature of the dying role will allow better delineation and, therefore, redress of its misuses.

### IMPLICATIONS FOR CLINICIANS AND THEIR PATIENTS AND FAMILIES

Clinicians are in a unique position to help patients and caregivers find their most suitable and

helpful role. Patients and families who are encouraged to hope for cure will likely retain the expectations of the sick role rather than the dying role and may seek futile interventions, many of which cause suffering and are costly.<sup>58,59</sup>

Clinicians should present relevant information about the patient’s condition and should work with patients and families to negotiate realistic goals for care. Various other members of a clinical interdisciplinary team, such as a social worker, counselor, nurse’s aide, or pastor, may help a person with other tasks associated with the dying role—tasks of adjusting to lost dreams and lost physical capacities and lost social roles, or tasks of engaging in the final growth phase or last rites of passage. All these facilitations with role related tasks are easier if the clinician has a clear sense for what the tasks tend to be and when they tend to be relevant. To assist this clarity among clinicians, medical education texts and programs can include descriptions of the dying role in their materials. Clinicians who have a full sense of the importance of the role can provide informational materials (brochures, worksheets, websites, etc.), offer public talks, and make referrals to related services such as support groups that include a focus on the tasks, and so forth.

Also important, clinicians are in a unique position to minimize barriers to entering the role and to minimize misuses of the role. For instance, clinicians can help optimize access to hospice and palliative care by making timely referrals or calling for timely consults. It should be a priority for clinicians to be competent to and to actually deliver excellent symptom control and the psychosocial aspects of comprehensive care. Clinicians should also address any relevant gap in knowledge, or any situational barrier such as a local medical culture where aggressive intervention has taken over in the patient’s care plan as an automatic expectation. Similarly, clinicians can preempt and redress misuses of the role when they detect it. Competent management of prognostic information should prevent a person entering the role prematurely. Alternatively, for the patient with a clearly limited prognosis, the clinician can encourage the person to realize the benefit of engaging in the tasks of dying. Similarly, clinicians can foster the social endorsement of the dying role, for instance, by making it clear to colleagues that reducing attention to a dying person is not an option for the clinical team.

## CONCLUSION

In conclusion, we are persuaded that roles are as relevant during the last stage of the life cycle as at any other stage. Because an understanding of the dying role, like other roles, has the capacity to guide and foster a good engagement in the process, we believe that it needs to be part of the conscious understanding that clinicians have so that they can impart the benefits of this role to patients and families. Lack of awareness of a dying role impedes good deaths and needlessly fails to ameliorate the psychosocial suffering of dying and bereaved people.

Toward the end of helping to redress its absence, we have reexamined the dying role and have identified three of its key elements. The practical element involves the management of physical aspects of illness and the concrete tasks of preparation for death. The relational element involves engaging with others as sub-roles are enacted and transitions are accomplished. The personal element involves tasks that foster personal growth, coming to terms and leaving those who will be bereaved with as much resilience as possible. Also toward the end of increasing the healthy integration of the dying role among other roles in society, we have identified some of the barriers that appear to stand between the present state of affairs and that goal.

While the position we have taken and the model we have proposed is grounded in role theory and in the practice of and scholarship from hospice and palliative care, further research is necessary to either validate or adjust the model and to develop tested methods to assist people with an optimal engagement with the role.

## ACKNOWLEDGMENTS

We appreciate the helpful comments of members of the Group on Illness and Human Potential.

## REFERENCES

1. Corr CA, Nabe CM, Corr D: *Death & Dying, Life & Living*, 5<sup>th</sup> ed. Belmont, CA: Thomson Wadsworth, 2006.
2. Edson M: *W;t: A play*. New York: Faber & Faber, 1999.
3. Deathbed Scene [artwork] (c.1440). In *The Hours of Catherine of Cleves* [illuminated manuscript]. New York: Pierpont Morgan Library.
4. Parsons T: Definition of health and illness in the light of American values and social structure. In Jaco EG (ed): *Patients, Physicians, and Illnesses*. Chicago: University of Chicago Press, 1972, pp. 97–117.
5. Glaser BG, Strauss AL: *Time for Dying*. Chicago: Aldine, 1968.
6. Bauman Z: *Mortality, Immortality, and Other Life Strategies*. Cambridge: Polity Press, 1992.
7. Baudrillard J: *Symbolic Exchange and Death*. London: Sage, 1993.
8. Seale C: *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge: Cambridge University Press, 1998.
9. Field D, Clark D, Corner J, Davis C (eds): *Researching Palliative Care*. Buckingham: Open University Press, 2001.
10. Charmaz K: Stories and silences: Disclosures and self in chronic illness. *Qual Inquiry* 2002;8:302–328.
11. Charmaz K: *The Social Reality of Death: Death in Contemporary America*. Reading, MA: Addison-Wesley, 1980.
12. Lawton J: Contemporary hospice care: The sequestration of the unbounded body and 'dirty dying.' *Sociol Health Illness* 1998;20:121–143
13. Scitovsky AA: "The high cost of dying": What do the data show? 1984. *Milbank Q* 2005;83:825–841.
14. Institute of Medicine: *Approaching Death: Improving Care and the End of Life*. Washington, D.C.: National Academy Press, 1997.
15. Goold SD, Williams B, Arnold RM: Conflicts regarding decisions to limit treatment. *JAMA* 1999;281:937–941
16. Ferraro KF: Aging and role transitions. In: Binstock RH, George LK, (eds): *Handbook of Aging and the Social Sciences*, 5th ed. San Diego: Academic Press 2001, pp. 313–330.
17. Hendricks J: Structure and identity—Mind the gap: Toward a personal resource model of successful aging. In: Biggs S, Lowenstein A, Hendricks J, (eds): *The need for theory: Critical approaches to social gerontology*. Amityville, NY: Baywood Publishing Company, 2003, pp. 63–87.
18. Exley C: Review article: The sociology of dying, death and bereavement. *Sociol Health Illness* 2004;26:110–122.
19. Field D: Awareness and modern dying. *Mortality* 1996;1:255–265.
20. Biddle RJ: *Role Theory: Expectations, Identities, and Behaviors*. New York: Academic Press, 1979, p. 56.
21. Shaw ME, Constanzo PR: *Theories of Social Psychology*, 2nd ed. New York: McGraw-Hill, 1982.
22. Heiss J. Social role. In: Rosenberg M, Turner RH (eds): *Social Psychology: Sociological Perspectives* New York: Basic Books, 1981, pp. 94–129.
23. Hewitt JP: *Self and Society: A Symbolic Interactionist Social Psychology*. Boston: Allyn & Bacon, 1991.



24. Brown A: *Social Processes of Aging and Old Age*, 2nd ed. Saddle River, NJ: Prentice Hall, 1996.
25. Lopata H: Social roles. In: Maddox GL (ed): *The Encyclopedia of Aging*, 3rd ed. New York: Springer Publishing Company, 2001, pp. 945–946.
26. Baltes PB, Baltes MM: *Successful Aging: Perspectives from the Behavioral Sciences*. Cambridge, UK: Cambridge University Press, 1990.
27. Moen P: A life course approach to postretirement roles and well-being. In: Bond LA, Cutler SJ, Grams A (eds): *Promoting Successful And Productive Aging*. Thousand Oaks, CA: Sage Publications, 1995. pp. 239–257.
28. Erikson EH: *Life History and the Historical Moment*. New York: Norton, 1975.
29. Knight SJ, Emanuel LL: Processes of adjustment to end-of-life losses: A reintegration model. *J Palliat Med* (in press).
30. Byock I: *Dying Well*. New York: Berkley Publishing Group, 1997, pp. 59–84.
31. Kassenbaum G, Bauman B: Dimensions of the sick role in chronic illness. In: Jaco EG (ed): *Patients, Physicians, and Illness*. New York: Free Press, 1972, pp. 130–144.
32. Noyes R, Clancy J: The dying role: Its relevance to improved patient care. *Psychiatry* 1977;40:41–47.
33. Parker-Oliver D: The social construction of the “dying role” and the hospice drama. *Omega* 1999–2000; 40:493–512.
34. Seale C: Changing patterns of death and dying. *Soc Sci Med* 2000;51:917–930.
35. Glaser BG, Strauss AL: *Awareness of Dying*. Chicago: Aldine, 1965.
36. Saunders C: *Care of the Dying*. London: Macmillan, 1959.
37. Lynn J: Measuring quality of care at the end of life: a statement of principles. *J Am Geriatr Soc* 1997;45: 526–527.
38. Singer PA, Martin DK, Kelner M: Quality end-of-life care: patients’ perspectives. *JAMA* 1999;281:163–168.
39. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA: In search of a good death: observations of patients, families, and providers. *Ann Intern Med* 2000;132:825–832.
40. Emanuel LL, Alpert H, Baldwin D, Emanuel EJ: What terminally ill patients care about: Toward a validated construct of patients’ perspectives. *J Palliat Med* 2000; 3:419–431.
41. Ferris FD, Balfour HM, Bowen K, Farley J, Hardwick M, Lamontagne C, Lundy M, Syme A, West PJ: A model to guide patient and family care: based on nationally accepted principles and norms of practice. *J Pain Symptom Manage* 2002;24:106–123.
42. Shanahan MJ, Hofer S, Miech R: Planful competence, the life course, and aging: Retrospect and prospect. In: Zarit S, Pearlin L, Schaie KW (eds): *Personal Control in Social and Life Course Contexts*. New York: Springer Publishing Company 2003, pp. 189–211.
43. Elder GH, Jr: The life course and human development. In Lerner RJ (ed): *Handbook of Child Psychology: Volume 1. Theoretical Models of Human Development*. New York: Wiley, 1998., pp. 939–991.
44. Miles SH, Koepf R, Weber EP: Advance end-of-life planning research review. *Arch Intern Med* 1996;156: 1062–1068.
45. Kit’s Story. ([www.lastchapters.org](http://www.lastchapters.org)) Last accessed March 20, 2004.
46. Hart M: Pastoral aspects of palliative care. In: Emanuel L, Librach L (eds): *Palliative Care*. Philadelphia: Elsevier Saunders, 2006.
47. Pat’s Story. ([www.lastchapters.org](http://www.lastchapters.org)) Last accessed Retrieved March 20, 2004.
48. Suzanne’s Story. ([www.lastchapters.org](http://www.lastchapters.org)). Last accessed Retrieved March 20, 2004.
49. Iolene’s Story. ([www.lastchapters.org](http://www.lastchapters.org)) Last accessed Retrieved March 20, 2004.
50. Leung K-L, Chiu T-Y, Chen C-Y: The influence of awareness of terminal condition on spiritual well-being in terminal cancer patients. *J Pain Symptom Manage* 2006;31:449–456.
51. Walter T: Historical and cultural variations on the good death. *BMJ* 2003;327:218–220.
52. Carr D, House J, Wortman C, Nesse R, Kessler R: Psychological adjustment to sudden and anticipated spousal loss among older widowed persons. *J Gerontol Soc Sci* 2001;56:S237–S248.
53. Timmermans S: Death brokering: Constructing culturally appropriate deaths. *Social Health Illness* 2005; 27:993–1013.
54. Hoyert DL, Heron MP, Murphy SL, Kung H: *Deaths: Final Data for 2003. National Vital Statistics Reports*, Vol. 54, Number 13. Hyattsville, MD: National Center for Health Statistics, 2006.
55. Ms. Wein’s Story. ([www.lastchapters.org](http://www.lastchapters.org)) Last accessed Retrieved March 20, 2004.
56. Pat’s Story. ([www.lastchapters.org](http://www.lastchapters.org)) Last accessed Retrieved March 20, 2004.
57. Prigerson HG: Socialization to dying: Social determinants of death acknowledgement and treatment among terminally ill geriatric patients. *J Health Soc Behav* 1992;33:378–395.
58. James N, Field D: The routinization of hospice: Charisma and bureaucratization. *Soc Sci Med* 1992;34: 1363–1375.
59. Clark D: *The Sociology of Death*. Oxford: Blackwell, 1993.
60. Covinsky KE, Goldman L, Cook EF, Oye R, Desbiens N, Reding D, Fulkerson W, Connors AF Jr., Lynn J, Phillips RS: The impact of serious illness on patients’ families. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *JAMA* 1994;272:1839–1844.

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## Additional Recommended Resources

Medical information

[www.caresearch.com.au](http://www.caresearch.com.au)

<http://www.advancecareplanning.org.nz>

Christian books

*Don't Waste your Cancer* John Piper. Free e-book available at [www.desiringgod.org](http://www.desiringgod.org)

*The Healing Promise*, Richard Mayhue (Mentor; Revised edition edition (March 20, 2009))

*Heaven*, Randy Alcorn (Tyndale Momentum (December 8, 2011))

*The Wonder of Heaven*, Ron Rhodes (Harvest House Publishers (February 1, 2009))

*The Glory of Heaven*, John MacArthur (Crossway; 2 edition (May 31, 2013))

*The Art of Dying Well*, Ian Kilgour (for a review and access to the book see here:

<https://candour.presbyterian.org.nz/2017/09/13/the-art-of-dying-well-by-ian-m-kilgour/>)

# Part Three: Theology and Ethics

## Theology

### “In Sure and Certain Hope”: Theological Questions and concerns

The following is an extract from the General Synod of The Anglican Church of Canada resource called *In Sure and Certain Hope: Resources to Assist Pastoral and Theological Approaches to Physician Assisted Dying (Faith, Worship and Ministry: Task Force on Physician Assisted Dying)* pp. 7-13. The complete text is available free here: <https://www.anglican.ca/wp-content/uploads/In-Sure-and-Certain-Hope.pdf>. The Taskforce consisted of:

- The Reverend Canon Eric Beresford. (Diocese of Toronto) Theologian and Ethicist; Rector of St. Timothy’s Anglican Church, Toronto; Past President, Atlantic School of Theology
- Ms. Louisa Blair, M.A. (Diocese of Quebec) Medical Researcher and Writer
- Dr. Anne F. Doig, M.D., CCFP, FCFP, LID. (Diocese of Saskatoon) Associate Clinical Professor of Obstetrics and Gynecology, University of Saskatchewan; Family Physician; Past President of the Canadian Medical Association
- Reverend Canon Douglas Graydon, M.Div., M.Ed. (Diocese of Toronto) Coordinator, Chaplaincy Services, Diocese of Toronto; Previously Spiritual Care provider, Casey House HIV/AIDS, and chaplain, Princess Margaret Cancer Care Palliative Care
- Dr. Juliet Guichon, SJD. (Diocese of Calgary) Assistant Professor in Community Health Sciences, Cumming School of Medicine, University of Calgary
- The Rev’d Dr. Ian Ritchie, PhD. (Diocese of Ontario) Adjunct Professor, Queen’s University Theological College, in pastoral ministry with the dying since 2002.
- Dr. Janet Storch, RN, PhD. (Partner from the Evangelical Lutheran Church in Canada) Professor Emeritus of Nursing, School of Nursing, University of Victoria

## INSIGHTS FROM SCRIPTURE AND TRADITION

The approach taken by *Care in Dying* was to dive directly into some of the most controverted issues with respect to biblical witness. The most difficult questions still remain with us: the issue of suicide, the notion of life as gift, and the meaning of suffering. In each of these areas, the concern of the task force at the time was to elucidate and differentiate between acceptable and non-acceptable theological approaches, setting up contrasting views. The key points, with further elucidation, follow.

## SUICIDE

*Care in Dying* pointed out clearly that none of the biblical passages that seem to refer to suicide<sup>3</sup> can be applied to the question of assisted dying in the context of a life maintained by intensive and often dehumanizing technological intervention, or in the face of unbearable pain and suffering.

In addition, the document acknowledged how the church’s approach to the question of suicide has changed from one of a blanket condemnation of the act of suicide to one of compassion and pastoral care for the one driven to suicide and to their family and loved ones. This shift has been driven both by a fresh articulation of the implications of the call to live in ways that reflect the unbounded love and compassion of God,

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3. Examples cited in *Care in Dying* include: 2 Samuel 17:23; 1 Kings 16:18-19; Matthew 27:3-5

and also by a more nuanced understanding of the situation, health, and motivating factors that might lead an individual to believe that the only viable option in front of them is to take their own lives.

The church *no longer sees as acceptable* interpretations of the motives for suicide cast in terms of lack of courage, unfaithfulness, or in terms of the rejection of God's will. We have also become increasingly skeptical of our capacity to understand and interpret the work of God in the life of another person. And though we have a long way to go, Christians have benefitted from advances in public awareness and professional education regarding mental illness. Pastoral care of those with suicidal ideation begins in the seeking of immediate qualified critical psychiatric care and appropriate medical intervention. Questions of situation and cause need to be assessed within the context of medical treatment wherein mental health diagnosis and treatment are involved.

## SUFFERING

A distinction needs to be made between suffering for the sake of the Gospel, and suffering within the human condition. When St. Paul speaks of suffering, for example, it is a suffering for the Gospel that comes as a result of his living out of his faithful response to the call of God. This is one sort of suffering which has its own theological meaning.

That form and meaning of suffering must be differentiated from the pain and suffering that is experienced as part of the human condition with its vulnerability to mental illness and physical sickness, aging processes, injury, suffering, and death.

*Care in Dying* rejected the claim that such suffering might be simply viewed as "devoid of purpose, and thus without redemptive value"<sup>4</sup>

4. P21 discussing the report of the Episcopal Diocese of Newark from which this quote is taken.

5. Zizak, *The Puppet and the Dwarf*, p.125

and strove to be more nuanced. The report acknowledged that suffering might be meaningful. However, it also noted that suffering might be devoid of redemptive value in and of itself. It still remains to be asked for whom this suffering might be meaningful. How is this sense of meaning to be established, and by whom?

The *Book of Job* has been upheld as profound wisdom tradition about the nature of human suffering, and has itself suffered from its vulnerability to misinterpretation. Looking closely at the biblical story of Job, we see that Job and his comforters seek to ascribe meaning and purpose to the mounting catastrophes that Job experiences. The interventions of the comforters are particularly problematic, but even Job's own search for meaning in the end comes face to face with the utter and impenetrable mystery of the being of God. In the face of this, all attempted explanations of human experience function ideologically.

Job's properly ethical dignity resides in the way he persistently rejects the notion that his suffering can have any meaning, either punishment for his past sins or the trial of his faith, against the three theologians who bombard him with possible meanings—and, surprisingly, God takes his side at the end, claiming that every word that Job spoke was true, while every word of the three theologians was false.<sup>5</sup>

Compare this with biblical scholar Walter Brueggemann's observation that, "The friends are dismissed because they had settled for an ideological conclusion, without taking into account the problematic of lived experience. The response to the encounter with the mystery of human suffering is not mere silence." As Brueggemann further clarifies, "Yahweh does not want ideology to crush experience. And that

leaves only two parties to draw the most authentic of conclusions: Yahweh and Job, face to face.”<sup>6</sup>

If this encounter of the individual sufferer with God in faith is indeed the place where the mystery of their seemingly incomprehensible suffering is addressed (we cannot simply say resolved) and meaning evoked, then we as the church need to be reticent about proposing generalizable solutions. Of course, we believe that there is meaning, but it is a meaning for which we listen in the encounter between God and the patient, not one which we interpose to frame that encounter and define it.

## LIFE AS GIFT

The scriptures affirm that life is a gift. However, the notion that the choice for death represents a disrespectful abandoning of that gift is one that comes from later periods in the Christian tradition. *Care in Dying* draws particular attention to the views of Augustine of Hippo and Thomas Aquinas. Augustine argued in his highly influential *City of God* that suicide amounts to cowardice in the face of pain and suffering. Aquinas argued from natural law that suicide violates our love of self and our instincts to self-protection. He builds on this, theologically, to say that suicide offends God who has given us life, and hurts the human community of which one is a part.

Augustine and Aquinas, arguably, set the stage for the development of Western Christian theology, and so it is not strange to find their approaches to this matter sounding somewhat familiar.

However, in each case, these two heavyweights of theology were doing what theologians do: bringing the lens of the culture,

6. Brueggemann, *Theology of the Old Testament*, p.391.

7. For example, a close reading of John Donne’s *Biathanatos*, rather easily dismissed in *Care and Dying* might prove provocative and rewarding.

scientific knowledge, and philosophy of their day to bear on the Christian story. And those philosophic presuppositions were precisely of those times, the 5th and the 13th centuries respectively.

Given the shift in Anglican thinking about suicide, we may need to rethink the easy assumption that receiving life as gift means that we cannot faithfully decide that the gift is one that we must now let go. Already in the case of the withdrawal of treatment we recognize that life is not an end in itself, and that the approach of death need not be resisted by all available means.

If the chief purpose of life is to know God and to enjoy God for ever, is it possible to conceive of circumstances where a person might faithfully conclude that this purpose could no longer be furthered by the extension of their life and might choose, not merely to cease to resist the approach of death, but to actively embrace it?

To approach this question helpfully would require a more nuanced read of the tradition<sup>7</sup>, including its minority voices, than we are able to offer here. It would require as well a more intentional listening to the experience of those who see no way in which their continued living can contribute to the ends of the life for which the gift was received.

• • •

There remain a number of theological commitments to be addressed:

## CARE AND COMMUNITY

Understandings of care, and how those understandings shape and express community, lay at the heart of the reflections in *Care in Dying*. Indeed, the trajectory of that document

was in many ways set by the way it answered the question of what constitutes care. In seeking to answer the question of whether a decision to participate in the ending of life could be construed as an act of care, the study was in some ways quite tentative. In the end however, that question was answered in the negative. The decision that there were problems so construing the ending of life as care were linked to questions of intentionality.

Perhaps a more telling question at this point might be to do with how our actions may be construed as examples of care. While it is fairly obvious that palliation and pain relief are acts that show our continued care for a patient for whom we can offer no cure, killing is a much more ambiguous act. (p.28)

Killing is more ambiguous because it can more easily be construed as an act of abandonment, a decision that the patient's life is not worth living and therefore not worth our continued investment in care. If, as *Care in Dying* insists, intentionality is important, then surely the points to be looked at are not simply whether we intend death or pain relief but also why we intend death and whether that intention is rooted in the life and dignity and choices of the one whose death we intend.

In other words, the question is more complex than *Care in Dying* allowed. It is not simply that we need to only intend death as an unfortunate, but unwilled consequence of our attempt to provide care, but also, and crucially, that in both dying and living, our care is articulated in terms of our covenant of presence to the other. This covenant is binding in health and in suffering, in life and in death. This is so because it reflects and communicates the presence of God to the other in their suffering and in their dying, and in the difficult and demanding decisions that might surround these experiences.

More careful reflection on the nature and demands of care is now particularly necessary in light of the decision of the Supreme Court of Canada. That decision consistently reduced the concept of care to the provision of therapy, in terms of medical treatment. It did not pay attention to the broader experience of care in terms of social, emotional, psychological, basic physical, and spiritual care, for example. The meaning of care and the demands it lays upon us need to be broadened.

A broadened view of matters of care, community, and conscience give rise to a complex of questions. *Care in Dying* asked whether a decision for physician assisted dying might be a response to the suffering not only of the dying but also of those who accompany them on that process. What constitute healthy relationships amongst caregivers, patient and supportive community in the patient's process of discernment? How does a refusal to provide assistance in dying represent a commitment to continue with care? What does care look like in this context? What happens when my conscience is in conflict, in either direction, with the decision of the patient? What needs to be done within this conflict? How do I tend to my conscience as well as to the patient in a situation of pastoral care in which I am uncomfortable with the patient's decision? These are the sorts of questions that will be dealt with later in this document.

## INTENTIONALITY AND RATIONALITY

There have been many debates over recent years concerning the role of intentionality. What does it mean to intend to do something? In debates about physician assisted dying intentionality is primarily used to distinguish between acts all of which result in the death of the patient but in some of which that death was not the willed or desired outcome.

Yet, as *Care in Dying* noted, intentionality can, in this sense, be only one part of the picture. While it is true that a foreseen consequence of our actions may not be what we intend, that it is foreseen means that we have at least some level of responsibility for it as an outcome. Perhaps more helpful in our context is the recognition that intentionality is about rationality and about narrative.

One of the things that makes a human action an action and not merely a reflex is that it is intended. If I am struck on the knee, I do not intend to kick the person in front of me. It is simply a reflex action over which I have no control. For something to be an action, at least in the moral sense, it must be something that I intend, something that I choose either explicitly or at least implicitly. This has a number of consequences.

First, it means that actions, properly so called, are expressions of who I am as a person, they reflect my intentions and in order to do so those intentions must be related to the wider narrative of who I am. I cannot simply intend anything, but only those things that make sense of my character, wider purposes, values, and commitments.

This means that what I might be able to intend changes over time as my character is shaped and reshaped by my intended actions. It means that the rationality of moral actions is in the end a form of narrative rationality because it is about rooting those actions within the story of a life in the broadest sense.

Finally, this also means that the task of moral understanding is in the end an interpretive one. I do not simply analyse actions on the basis of preformed rules and commitments, I consider actions in terms of the shape of a life. From a Christian perspective this means that I am attempting to understand how an individual life participates in and reflects the life of Christ into which my life has been incorporated at baptism.

## VULNERABILITY AND JUSTICE

This life into which we are incorporated is never merely about our individual lives. It is not a life that is lived for myself but rather one that shares in self-offering for the other. Christians have, from our beginnings, been concerned therefore for the well-being of the marginalized, the outsider to society.

In the area of physician assisted dying there are still reasons to be concerned about the impact of this change on those in our society who are most vulnerable. This is the reason why most groups advocating on behalf of those who live with disabilities have not welcomed this change. While advocating against the change in the law would not at this time be a practical or useful activity for the churches it is important that we continue to express concern for those who might be adversely affected. This is not simply a slippery slope argument. It is rather based in the complexity of how constitutional protections work and the experience of other jurisdictions where the initially narrow grounds for physician assisted dying became widened out of legitimate concern that some who might benefit were excluded under the initial definitions.

In the Canadian context this is particularly telling, as the conditions under which physician assisted dying will be made available remain in so many ways vague at this time. The regulations to be adopted will be crucial in ensuring that individuals are not either actively or implicitly coerced and that those who are vulnerable and at risk receive particular protection.

## DIGNITY AND ITS MEANING

Central to the debates concerning physician assisted dying, on all sides, is the question of the dignity of the human person. Yet, while all agree on affirming the dignity of the human person, there is little agreement on what that

means and little public reflection on the dangers or difficulties involved in various approaches to uphold such dignity. In our society dignity is most commonly linked to the capacity to be the author of one's own destiny. However, this is linked with understandings of human individuality and freedom that are difficult to maintain.

All of us wish to affirm the freedom of the individual, but as our discussion of intentionality made clear, this does not mean that individuals can simply do anything.

While we all understand that freedom as involving authorship of our own acts, the idea that this is done *ex nihilo* (*out of nothing*) is simply unsustainable. In truth, who we are, and therefore what we are free to choose and to do, is already to some degree shaped by our personal histories, our background, our education, our cultural and religious assumptions and many other factors. Any adequate and morally informative description of human freedom and its exercise needs to take into account the very real limitations involved in living out that freedom in real historical lives.

Further, the simple link of dignity with the capacity to be the author of our own lives rather than prejudges the issue for those persons whose capacities in this regard are significantly, and perhaps permanently diminished.

Others would argue that dignity is linked to relationship and is a product of the demands of human community. The point here is not that relationships confer dignity but rather that it is in our experience of those relationships that we are empowered to recognize and give voice to our inherent worth. While this approach to human dignity has much to commend it the danger is that it might be seen as reducing the dignity of those whose capacity for ongoing and sustained relationships is compromised.

In both of these approaches the difficulty is that dignity is only construed on the basis of the possession of certain qualities and capacities

and this once again may lead to a devaluing of those persons lacking those qualities. Perhaps the key point, however, is that the language of dignity is supposed to remind us that in decisions about the life of a person it is that person's life, inherent worth (however that is ascribed), values, hopes, aspirations, story, etc. that drive the decision-making process and not the imposition of interpretive frameworks from without, the imposition of what Zizak and Brueggemann would call ideology.

"*You matter because you are you.*" These are the words of Dame Cicely Saunders, expressing the foundational values of the modern palliative care movement. To uphold the intrinsic worth of the human person is to protect the very vulnerable members of society—those who have (or appear to have) little if any extrinsic value, because they do not have the capacity for full authorship or autonomy, and are not able to have the same sorts of relationships that more "productive" members of society have. This value challenges the linkage of dignity and worth with autonomy and ability to be in control of all aspects of one's life.

## CONSCIENCE

One of the matters that was touched upon in *Care in Dying* and which is increasingly important in our new context is that of the role of conscience. It will surprise some people that the principle that the conscience must always be followed (*conscientia semper sequenda*) is a key element of Catholic moral theology that has continued if not with greater importance in the churches of the reformation. The role of conscience grants to the individual believer the responsibility to be the author of his or her own decisions.

This responsibility cannot be ceded to another, even to the church. Having said that, individual Christians have a responsibility to educate their conscience and this means a responsibility to



engage seriously with the teaching and traditions of the church. A decision to place oneself at odds with a longstanding and widely held teaching is not to be taken lightly. However, changing social context can lead to situations in which that tradition can seem misleading, unduly burdensome, or even simply destructive.

Christians are not of one mind as to whether changes in the context of our dying are sufficient to change or qualify traditional views regarding assisted dying. In this context, especially given the changed legal situation, effective pastoral care will need to be quite clear in its respect for the conscience of the person making decisions around their own dying. At the same time, this is not to be construed as pastoral indifference, or even abandonment. We can minister with respect and care even in situations that will unfold in ways that make us uncomfortable. Indeed, it is arguable that this is where our pastoral presence is most eloquent and important.

## HOPE

As Christians we are called to lives shaped by hope. Hope involves the commitment that, whatever our circumstances, God is at work for our good (Ro 8:28 c.f. Mat7:11). It stands opposed to despair. At the same time hope is not to be confused with a passivity that is unresponsive to our circumstances. Hope requires that we cooperate with God in the purposes that God is working out in our lives. Under all circumstances this will involve seeking what God is doing in our lives. This is true even in adverse circumstances, and it is not contrary to the notion that hope might include the embrace of our death.

Paul, writing to the Philippian Church chooses life for the sake of the Philippian Christians, although he clearly indicates that his

personal hope is to “depart and be with Christ” (Philippians 1:23). Further, the willing embrace of death as an expression of hope in God’s faithfulness lies at the heart of our faith in the work of Christ.

Neither of these examples can be seen as either the act of, or the willing of, suicide, because neither of them are acts of despair. They raise for us the challenging pastoral question of how we might assist those faced with decisions around the end of life to make whatever decision they chose in faith and hope and in the embrace of God’s presence to them.

## PROVIDING ALTERNATIVES

Having said this, if indeed decisions are to be made out of the commitments of those about whom decisions are made, then there need to be genuine alternatives and this currently does not seem to be the case.

In *Care in Dying* the argument was made that to move towards physician assisted death at a time when there were health care cuts and utterly inadequate provision of palliative care might be seen as cynical rather than caring. While it is now clear that the provision of such alternatives cannot function as a bar to patients making decisions to seek assistance to end their lives we remain of the view that this change will not reflect the intended affirmation of the dignity of patients unless there are genuine alternatives amongst which they can discern real and significant choices.

Urgent attention therefore needs to be given to the provision of appropriate (we would say excellent) levels of palliative care, social support and pain management so that any decision to avail oneself of physician assisted dying will indeed be a reflection of what expresses the patient’s dignity and not an act of desperation or fear.

## A Māori Perspective: Te Upoko o te Ika Submission

Te Hui Amorangi ki te Upoko o te Ika Submission to the Justice Select Committee: End of Life Choice Bill (20 February 2018)

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We would like to make an oral submission.

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Tena koutou nga mema o te Justice Select Committee.

This submission is made on behalf of Te Hui Amorangi ki te Upoko o te Ika. Our Amorangi is one of five Tikanga Maori Amorangi that make up the Tikanga Maori membership, Te Pihopatanga o Aotearoa, within the 3-Tikanga Anglican Church of Aotearoa, New Zealand and Polynesia.

This submission was prepared from korero at a Te Hui Amorangi ki te Upoko o te Ika hui held on Friday 16<sup>th</sup> February in Otaki. The large majority of our Amorangi represented at this Amorangi hui, are against the proposed End of Life Choice Bill introduced to the House by David Seymour. It was the agreement at this Te Hui Amorangi ki te Upoko o te Ika hui that this submission would be written to recommend no change be made in the existing law.

### Reasons for opposing the End of Life Choice Bill

#### *Maori Tikanga*

This korero is from a Pakeha Tikanga and has been forced on us. This is not our Tikanga. This is also a reason why there is 'silence,' or 'limited' or 'no comment' from Maori on this Bill. This is why we thought it important to have this korero within our Amorangi because we need to enter this discussion from a Tikanga Maori perspective. If this Bill is passed by Government, this decision has the potential to impact on all our whanau, hapu and iwi in the future.

This 'choice,' this 'decision,' this 'right to choose,' for Maori does not operate in a vacuum. The impact of this type of decision affects not only whanau, but hapu and iwi. Any decision affecting a whanau member, needs to incorporate all whanau in making the decision. As whanau, we are also answerable to our Atua, our Tupuna, and our people for any decisions we make that impact on all those we whakapapa to. We are also answerable to our mokopuna and future generations. What we decide now impacts on the present, but also the past and the future.

Our role as whanau is to strengthen and enable our whanau. We prolong life as long as we can. So we stick with our whanau for as long as they are here with us. Whanau are our living taonga. Our tikanga is to prize and honour life. Respect for human dignity is important for us as Maori. Human dignity is about all whanau, hapu and iwi taking care of all those they whakapapa to. Whanau and all the loved ones of a person who is in the process of passing from this world into the next, will always be right beside their loved one for 24 hours a day, caring for any need, including karakia, himene and waiata, mirimiri and rongoa, and providing loving tenderness and touch. Whanau will often take shifts in caring for their loved one right up until they pass, and will continue this care and attention right up until they are interred in their whanau urupa or cemetery, or cremated. They are never left alone. This time is a special and sacred time for whanau.

This time of life has an immediate and lasting impact on all those who are assisting in the care of a loved one, and in the process of preparing and assisting their loved one for passing. This is an expected and natural role for all whanau to do for their loved ones – it is a whanau responsibility of care and aroha.

There are Tikanga Maori processes that need to be completed before someone passes, and when they are close to death. This transitions the way for our loved ones to pass. The signs (tohu wairua)

are there when someone is close to passing. When it is time, there will be signs that indicate that our loved one is close and ready to pass. We cannot stop it. This happens in God's time.

The 'tuku' karakia is commonly conducted immediately following death. 'Tuku' is a traditional Maori protocol to transition and release one's wairua to the next world, to our ancestors, and our Atua - Tūkua kia haere, tūkua kia rere.

### *'Choice'*

Having the 'choice' to end one's life, and the principle of 'individual rights,' come from a Western perspective and focus on the individual and not on whānau. This perspective and focus does not consider Maori Tikanga. This is not our tikanga. It's never been in our thoughts and it's never been in our dialect.

We are also in agreement with the Inter-Church Bioethics Council (ICBC) submission to the Justice Select Committee, where they say in their submission:

"Of great significance, the current discussion is largely a rationalist Pakeha conversation. Many cultures in New Zealand other than the majority Pakeha culture have traditional ways of managing death and dying in family/whānau settings. Our conversations and research identify that euthanasia/assisted suicide has no equivalent in language or practice in Māori and Pacific people practices. Therefore, the current debate risks imposing on New Zealand culture a largely individualistic worldview without adequately considering other perspectives. Within Māori and Polynesian communities, euthanasia/assisted suicide is not part of everyday reality or something readily discussed. For many Māori the tribal custom of karanga aituā means that talk about death will 'call it down', which could further limit discussing the issue of euthanasia/assisted suicide. However, the Bill now brings this issue into the open for us all, and the result of this Bill may affect any one of our whānau. That is why there is a call for Māori and Polynesian families to discuss this Bill, and its impacts on whānau, hapu and iwi. As Tess Moeke-Maxwell and colleagues state, 'the dying and their whānau are proactive in doing whatever they can to ensure a high quality of life is achieved to enable the individual to live for as long as possible and as comfortably as possible' – 'They do not give in easily to death.'"<sup>2</sup>

### *Our Faith*

Within our Biblical faith, the focus for us all as whānau, hapu and iwi is on preserving, prolonging, safeguarding and respecting the sanctity of life, and not taking life. We are all God's DNA. God has given us life, and it is he who takes it away when our time is at an end on this earth, not us. God is the giver of life. "My times are in your hands" (Psalm 31: 15). Having a strong faith as we do in Haahi Mihinare, the Anglican Church, we can get through any hardships and challenges in life, along with the love of our whānau in life and in Christ.

### *General concerns*

Amorangi members were concerned that if this Bill was passed by Government and brought into law, that the medical staff who are authorised to assist a person to die, will be going against the Hippocratic Oath that they signed on becoming a medical professional. The impact on medical

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<sup>2</sup> Tess Moeke-Maxwell, Linda Waimarie Nikora and Ngahuia Te Awekotuku. "Māori End-Of-Life Journeys". In Human Development: family, place, culture 2nd ed, W Drewery and L Bird Claiborne eds.. North Ryde: McGraw- Hill Education, 2014. pp. 382-383. & Tess Moeke-Maxwell et al., "End-of-Life Care and Māori Whānau Resilience". p. 145.

personnel who carry out assisted medical suicide for a patient, could result in negatively affecting their own wellbeing – spiritual, physical and emotional.

Generally, mental health issues impacting on whanau health and wellbeing are enormous and varied (eg. historical and intergenerational trauma). Concern has been expressed by our Amorangi that those within our whanau who are experiencing and are affected by mental health issues are vulnerable. Their ability to determine what is 'intolerable' and what is 'unbearable suffering' may be affected.

Concern has also been expressed by our Amorangi in regards to what is meant by 'unbearable suffering' and what is 'tolerable.' The measurement of 'unbearable suffering' and 'tolerance' in terms of pain (whether physical, emotional or spiritual) is not universal. We know within our own life experiences, whanau, hapu and iwi, that there is a difference in the threshold of pain for males and females. What is 'tolerable' and what is 'intolerable' is also dependant on context and each particular persons situation. For example, anecdotally and statistically Maori males are more likely to commit suicide than females.

Concern has also been expressed by our Amorangi that this Bill, if passed, gives too much power to the medical fraternity, who often hold a very different worldview from us as Maori.

### Conclusion

Thank you for this opportunity to share some of our korero on the End of Life Choice Bill. As mentioned, the large majority of our Amorangi represented at this Amorangi hui held on Friday 16<sup>th</sup> February 2018, are against the proposed End of Life Choice Bill introduced to the House by David Seymour. It was the agreement at this Te Hui Amorangi ki te Upoko o te Ika hui that this submission would be written to recommend no change be made in the existing law. We would appreciate the opportunity to make an oral submission also, where we could elaborate on our reasons for not supporting the proposed End of Life Choice Bill.

E te Ariki, nau nei matou i karanga ki au mahi.	Lord, you have called us to serve you.
Meatia kia hikoi matou i mua i tou aroaro,	Grant that we may walk in your presence:
whakaungia mai tou aroha ki o matou ngakau,	your love in our hearts,
tou pono ki o matou hinengaro,	your truth in our minds,
tou marohirohi ki o matou whakaaro,	your strength in our wills;
mo te taenga ki te tino tauranga,	until, at the end of our journey,
ka mohio pu ki te hari, kua tau ki te haukainga,	we know the joy of our homecoming
ki te taanga manawa i roto i a koe,	and the welcome of your embrace,
I roto hoki i to matou Ariki, i a Ihu Karaiti.	through Jesus Christ our Lord.
Amine.	Amen. <sup>3</sup>

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<sup>3</sup> The Anglican Church in Aotearoa, New Zealand and Polynesia. (1989). A New Zealand Prayer Book: He Karakia Mihinare o Aotearoa. Genesis Publications, Christchurch, NZ. pp. 414-415

## InterChurch Bioethics Council Submission to the Justice Select Committee: On the End of Life Choice Bill

The InterChurch Bioethics Council (ICBC) is an ecumenical, cross-cultural body supported by the Anglican, Methodist and Presbyterian Churches of Aotearoa, New Zealand ([www.interchurchbioethics.org.nz](http://www.interchurchbioethics.org.nz)). Its role is to increase the knowledge and understanding of church members and the wider community, of the spiritual, ethical and cultural issues connected to biotechnology and related issues, and enable and encourage citizens to take action on their own behalf on these issues. ICBC members have between them considerable expertise and knowledge in science, ethics, theology, medicine and education.

In writing this submission **against** the proposed End of Life Choice Bill introduced to the House by David Seymour, the ICBC recognises that we do not represent all Anglicans, Methodists and Presbyterians, but that as a designated committee, we are providing our “expert” opinion following our own discussions, research and reading over the past 3 years and some limited wider consultation. Our submission will follow 8 areas that we would like to bring to the Justice Select Committee’s attention. **We would like to appear** before the committee to talk to our submission should the opportunity arise.

We would also like to remind the Justice Select Committee that over the past 2 years the Health Select Committee has undertaken a comprehensive process to determine public attitudes towards legislation permitting medically-assisted dying following the petition of “Maryan Street and 8,974 others” that sought to determine the public opinion on assisted suicide. Their report was presented to Parliament in August 2017, received 21,000 unique submissions and heard from 944 oral submission. The key finding was that “80% of submitters were opposed to a change in legislation that would allow assisted dying or euthanasia”.<sup>4</sup>

Before addressing these issues, we believe it is important to clarify terminology in this current debate. The term “assisted dying” we believe is inadequate as this confuses scenarios where the intention of the medical practitioner is actively to cause death with those where the intention is to relieve suffering. Where the intention is to cause death, this may be either through prescription of drugs which the patient takes (assisted suicide) or where the doctor administers a lethal dose of drugs (euthanasia). Where the intention of the medical practitioner is to relieve suffering, this may include withholding or withdrawal of treatment and administration of appropriate treatment through which “nature” is allowed to take its course and death is allowed to occur. This is not defined as euthanasia and is currently legal. For the purposes of our submission the term “euthanasia/assisted suicide, EAS” will be used.

We acknowledge that there is a small but significant population for whom the conditions of their death are horrendous and unacceptable. We would advocate for funding for research and access to resources that helps to alleviate this suffering. We acknowledge also that there will sometimes be family and even medical assistants who will quietly hasten death in these circumstances. However tragic these situations are we do not think the appropriate response is to give everyone the “right to die” or the “right to be assisted in dying”. The cost is too great – for the other vulnerable populations mentioned below, for doctors who have always seen their calling as maintaining life, not taking life, and for all older people who might begin to wonder if they have outstayed their welcome on earth. The enshrining of this right in law would have widespread and deepening repercussions for the way we understand life, and the callings and duties of life.

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<sup>4</sup> Health Select Committee, *Petition 2014/18 of Hon Maryan Street and 8,974 others*. Wellington: NZ Parliament, 2017, pg 6. [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24)

Indeed, much of the current debate centres on a patient's right to choose when and how to die in the face of a terminal illness. But the right to self-determination does not take place in a vacuum – no-one is completely free, we are embedded in family and society involving critical relationships, including a debt to future generations. Our personal freedom is always held alongside the rights of others, and from a Christian perspective, our personal rights must be considered alongside our responsibilities to others that reflect our love of God as indicated in the command to love both God and neighbour (Mark 12:28-32). In the face of suffering, the Christian and humane response is to maximise care/compassion for those in most need. Killing, however, is not a part of the arsenal of care/compassion for the dying.

### Reasons for opposing the End of Life Choice Bill

In acknowledging that euthanasia and assisted suicide have significant moral and ethical objections, there are also significant discrepancies in this legislation that we suggest make the End of Life Choice Bill untenable.

1. We believe the scope of the Bill is too large.  
The purpose of the Bill: “gives people with a terminal illness or a grievous and irremediable medical condition the option of requesting assisted dying” (part 1 clause 4).
- Provides “assisted dying” for NZ citizens 18+. This criterion is too arbitrary and open to legal challenge. As seen overseas, over time minors (those under 18) have also been granted permission for assisted suicide.<sup>5</sup> If death is a good/right for some it ultimately becomes seen as a good/right for all.
- with a terminal illness likely to end his or her life within 6 months – Medically speaking this is difficult to determine, and overseas evidence shows some people being given permission for assisted suicide living longer than 6 months. In Oregon 2014, the range of days between first request and death was 15-439 days.<sup>6</sup> Even Lecretia Seales was initially given only weeks to live and survived 3½ years.<sup>7</sup> Furthermore, significant discrepancies between clinical diagnosis before death and post-mortem findings suggests that misdiagnosis in up to 39% of cases is possible.<sup>8</sup> The problem here is that euthanasia/assisted suicide is a non-reversible ‘solution’, and the 6-month criterion (or any time frame) cannot be provided with absolute certainty.
- and in advanced state of irreversible decline and experiences unbearable suffering that cannot be relieved in a manner the person considers tolerable. In this context, ‘Unbearable suffering’ is self-defined and is effectively euthanasia/assisted suicide on demand. This criterion would allow for euthanasia/assisted suicide even if the patient rejected effective treatment on the basis they deem it intolerable.

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<sup>5</sup> <http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-grantedbelgium/7855620>

<sup>6</sup> Oregon Public Health Division: Oregon's Death with Dignity Act – 2014. <https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf>, pg 6.

<sup>7</sup> Macfie, R. (2015, January 8). Dying wishes. *The Listener*. Retrieved from <http://www.listener.co.nz/currentaffairs/health-current-affairs/dying-wishes/>

<sup>8</sup> Gavin D Perkins, Danny F McAuley, Sarah Davies and Fang Gao (2003). Discrepancies between clinical and post-mortem diagnoses in critically ill patients: an observational study. *Critical Care* 7:R129. <https://doi.org/10.1186/cc2359>. <https://ccforum.biomedcentral.com/articles/10.1186/cc2359>. Also see The Sydney Morning Herald. (2004, June 8). *Post mortem reveals euthanasia crusader clear of cancer*. Retrieved from <http://www.smh.com.au/articles/2004/06/08/1086460287366.html?from=storylhs>.

- Although this bill is framed to provide an Option for euthanasia/assisted suicide, we believe “option” is a loaded term, and one that is not simply a clear rational perspective. Our society projects certain values, including what we value in people - productivity, intelligence, physique – so that people can be made to feel a burden on relatives or society, or feel devalued by not fitting the social stereotype. For example, in the Netherlands there are moves to extend euthanasia/assisted suicide laws with a “completed life” bill.<sup>7</sup> The danger in the suggested law change provided by the End of Life Choice Bill, is that we may be providing a threshold beyond which a person’s life is seen as having little or no value instead of addressing how society hold and value people, especially the vulnerable.
2. The Bill does not properly characterise the current NZ situation (pg 2-3)
    - It prioritises the Lecretia Seales case. Although Justice Collins remarked that “The complex legal, philosophical, moral and clinical issues raised by Ms Seales’ proceedings can only be addressed by Parliament ...” all three petitions to the court based on the human right to die/choose death were rejected on legal grounds.<sup>9</sup> Ms Seales herself stated that she may not have used assisted suicide even if it was legal or the Judge had found in her favour.<sup>10</sup>
    - As evidence for a required law change, it is argued in the background to this bill, that the current law has treated with leniency those who have assisted terminally ill family members to end their life (Background pg 2). This however is evidence that the current law works, not that the law needs changing.
    - New Zealand First has asked for a binding public referendum on this issue. However, even if a referendum identified a majority position for euthanasia/assisted suicide, this would not mean that the public were suitably informed about the difference in terminology or the significant issues involved.
    - As previously mentioned, the claim that there is strong public support for a law change (background pg 2) is incorrect given the Health Select Committee 2017 finding was that “80% of submitters were opposed to a change in legislation that would allow assisted dying or euthanasia”.<sup>11</sup> This figure contradicts previous surveys indicating support for a change (2012, 2969 people 62.9% support; 2015, 2800 people 66% support).<sup>12</sup> These previous survey results reflect the level of public confusion about what the terms euthanasia/assisted dying mean. Significantly, 63.6% of all submissions to the Health Select Committee, equating to 82.5% of all submissions opposed to a law change, used no religious argument in their opposition to change.<sup>13</sup> The Health Select Committee process was an open process, with no leading questions but simply asked for public opinion. The scope of this report, the number of respondents, and the significance of the findings, means that the Health Select Committee report should have significant weight in the Justice Select Committee deliberations.
    - Of great significance, the current discussion is largely a rationalist Pakeha conversation. Many cultures in New Zealand other than the majority Pakeha culture have traditional ways of managing death and dying in family/whanau settings. Our conversations and research

<sup>9</sup> <https://www.stuff.co.nz/national/69112451/lecretia-seales-did-not-have-right-to-die-high-court-rules>

<sup>10</sup> <https://www.stuff.co.nz/national/69068898/Lecretia-Seales-lived-with-passion-determination-andautonomy>

<sup>11</sup> Health Select Committee, *Petition 2014/18 of Hon Maryan Street and 8,974 others*. Wellington: NZ Parliament, 2017, pgs 6, 15, 47. [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24)

<sup>12</sup> *ibid*, 14-15.

<sup>13</sup> Care Alliance. *Analysis of written submissions to the Health Select Committee’s investigation into ending one’s life*. May 5, 2017. <http://carealliance.org.nz/wp-content/uploads/2017/05/HSC-submissionsanalysis.pdf>.

identify that euthanasia/assisted suicide has no equivalent in language or practice in Māori and Pacific people

- practices. Therefore, the current debate risks imposing on New Zealand culture a largely individualistic worldview without adequately considering other perspectives. Within Māori and Polynesian communities, euthanasia/assisted suicide is not part of everyday reality or something readily discussed. For many Māori the tribal custom of karanga aituā means that talk about death will ‘call it down’,<sup>14</sup> which could further limit discussing the issue of euthanasia/assisted suicide. However, the Bill now brings this issue into the open for us all, and the result of this Bill may affect any one of our whānau. That is why there is a call for Māori and Polynesian families to discuss this Bill, and its impacts on whānau, hapu and iwi.<sup>15</sup> As Tess Moeke-Maxwell and colleagues state, “the dying and their whānau are proactive in doing whatever they can to ensure a high quality of life is achieved to enable the individual to live for as long as possible and as comfortably as possible” – “They do not give in easily to death”.<sup>16</sup>
3. Terminology within the Bill
- As defined in the Bill (Part 1:3) “assisted dying” means the administration by a medical practitioner of a lethal dose of medication to a person to relieve his or her suffering by hastening death.
  - The term “assisted dying” as defined above is inadequate as this confuses scenarios where the intention of the medical practitioner is actively to cause death with those where the intention is to relieve suffering. The Bill identifies 4 methods: ingestion or intravenous delivery by the person; or delivery through a tube or injection by a medical practitioner (part 2 clause 15). Where the intention is to cause death as outlined in the Bill this may be either through prescription of drugs which the patient takes and is correctly termed “assisted suicide”, or where the medical practitioner administers a lethal dose of drugs, is correctly termed “euthanasia”.
  - Where the intention of the medical practitioner is to relieve suffering, this may include the withholding or withdrawal of treatment and administration of appropriate treatment through which “nature” is allowed to take its course and death is allowed to occur. This is not defined as euthanasia/assisted suicide and is currently legal.
4. The Bill claims that relief of suffering and compassion is the motivation for this legislation (Purpose pg 1 and Part 1 clause 3).
- We acknowledge there are circumstances where individuals face unbearable suffering, however compassion is a societal value, not only for the individual. There are many arguments against assisted suicide that do not have a religious foundation, and there are

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<sup>14</sup> Tess Moeke-Maxwell, Linda Waimarie Nikora and Ngahuia Te Awekotuku. “Māori End-Of-Life Journeys”. In *Human Development: family, place, culture* 2nd ed, W Drewery and L Bird Claiborne eds.. North Ryde: McGraw- Hill Education, 2014.pp. 382-383.

<sup>15</sup> Mamari Stephens. *We need to hear the Māori and Pacific voices on the euthanasia debate*, Feb 21, 2016. <https://e-tangata.co.nz/news/we-need-to-hear-maori-and-pacific-voices>. Bishop Kito Pikaahu, *Māori perspective needed in death debate*, Dec 20, 2017. [https://www.waateanews.com/waateanews/x\\_news/MTgxMzU/National%20News/Maori-perspectiveneeded-in-death-debate](https://www.waateanews.com/waateanews/x_news/MTgxMzU/National%20News/Maori-perspectiveneeded-in-death-debate). Alice Guy. *End of Life Choice Bill sparks debate about euthanasia and Māori values*. Jan 20, 2018

<sup>16</sup> Tess Moeke-Maxwell, *et al.*, “Māori End-Of-Life Journeys”, pp. 382-383. Tess Moeke-Maxwell *et al.*, “End-of-Life Care and Māori Whānau Resilience”. p. 145. [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11977365](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11977365).



some that have their foundation in religious values. One such shared value is our understanding of love and compassion. Care and compassion contained within the view of unconditional love is about doing good without doing harm and identifies the intrinsic value and dignity to human life regardless of abilities or situation. Compassion is exercised in relationship with others so the ‘suffering’ of an individual does not happen in isolation. Nor does its treatment, or the choices an individual may wish to make.

- Respect for human dignity applies to everyone throughout life, and to humanity as a whole. In this context, the causing of death is seen as a harm, whereas compassion denotes walking alongside the other so as to not die alone, and where the relief of suffering can include not prolonging the process of dying. Furthermore, there is also the preferential care for the vulnerable within society, so that our compassion and care extends to create conditions where all can flourish. For those experiencing suffering, this includes the greater availability of palliative care; research into palliative medicine; and by listening to those who speak for the ‘disabled’ so that there is “nothing about us without us”.<sup>17</sup>
- This bill identifies the relief of suffering as the major motivator for law change. However, “suffering” is too broad a term and needs further definition. Suffering can be understood as:
  1. Pain - physical suffering which can be managed through medication, including terminal sedation near the end of life;
  2. Distress – physical/psychological suffering in situations for example when a patient can’t breathe. Again, this can be adequately managed through medication or medical interventions.
  3. Suffering – existential, where people feel they have no place, no value, no hope, no autonomy or are a burden. It is this form of suffering that surveys identify as the major reason for people wanting to use euthanasia/assisted suicide.<sup>18</sup>
- New Zealand is rightly concerned about the levels of suicide especially among young people, and men aged between 20 and 65 where the New Zealand rates are high compared with other OECD countries.<sup>19</sup> Suicide rates have reached their highest since records have been kept, and have risen three years in a row.<sup>20</sup> “From June 2014 to May 2015, 569 people are officially listed as having died by suicide or suspected suicide – the highest number ever recorded in New Zealand.” Furthermore, it is recognised that the rates for suicide are under-reported.<sup>21</sup> Do we want suicide (whether physician-assisted or not) normalised as an option when a person is in distress? Do we want to be a society that when someone takes their own life, our response is to say, “well that was their choice”? Furthermore, overseas studies

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<sup>17</sup> Margaret Somerville, *The Importance of Stories in the Euthanasia Debate: the risks and harms to vulnerable people outweigh any possible benefits.* <https://www.mercatornet.com/careful/view/the-importance-of-stories-in-the-euthanasia-debate/19452>

<sup>18</sup>

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year17.pdf> (2014). Also <http://www.theguardian.com/commentisfree/2015/sep/05/assisted-dying-suicide-bill-justin-welby-archbishop-canterbury>

<sup>19</sup> Glenn McConnell. *The highest rates of teen suicide in the developed world.* Last updated October 16, 2016. <https://www.stuff.co.nz/national/health/85305366/the-highest-rate-of-teen-suicide-in-the-developed-world>. Andy Fyers. *Unicef Report: New Zealand 34th out of 41 developed countries for child wellbeing.* Last updated June 15, 2017. <https://www.stuff.co.nz/national/93583589/unicef-report-wellbeing-of-kiwi-kids-languishes-behind-other-developed-countries>.

<sup>20</sup> Tina Law. *National suicide numbers rise three years in a row.* Last updated August 28, 2017. <https://www.stuff.co.nz/national/health/96217175/national-suicide-numbers-rise-three-years-in-a-row>. Jess McAllen. *Suicide toll reaches highest rate since records kept.* Last updated July 3, 2015. <http://www.stuff.co.nz/national/health/69920289/Suicide-toll-reaches-highest-rate-since-records-kept>

<sup>21</sup> Amy Maas. *The story of one woman, a suicide note, and blind justice.* Last updated May 29, 2016. <http://www.stuff.co.nz/national/health/80450197/the-story-of-one-woman-a-suicide-note-and-blind-justice>

show that allowing euthanasia/assisted suicide does increase the rates of unassisted suicide - in the Netherlands unassisted suicide rates have increased 35% over the 6 years up to 2015.<sup>22</sup>

#### 5. Safeguards for the Bill

- Part 2 clause 6 talks about conscientious objection and safeguards. Although a medical practitioner may refuse a request for euthanasia/assisted suicide, the Bill compels the medical practitioner to refer the patient to the SCENZ group – an appointed body that does not have an objection to assisted suicide/euthanasia [part 2, clause 7 (2), part 3 clause 19]. This overrides the professional autonomy of the health practitioner and forces him/her into colluding in the process.
- This undermines the safety processes in that the SCENZ group will refer the patient to a doctor that has no long-term relationship with the patient and is in no position to assess coercion or other underlying issues. This is of concern in that depression, the commonest factor in requesting assisted suicide or euthanasia, may be difficult to detect even when the doctor knows the patient well.
- In New Zealand the population at risk includes elderly people and people with disabilities. There is already concern about the level of elder abuse,<sup>23</sup> and older people have little or no power to resist subtle pressures that they should end their lives, and many worry that they may be a burden to other people. As indicated by the US states of Oregon and Washington, 40-60% of those who used legally prescribed lethal drugs to end their lives cited concerns that they would be a burden on their families as a factor in their decision to end their lives.<sup>24</sup>
- The Two-person safeguard (part 2, clause 10 and 11) has been shown to be inadequate in Oregon over time,<sup>25</sup> with one or both medical practitioners having no long-term relationship with the patient and evidence of “doctor-shopping”. Again, referrals to specialists provided by the SCENZ group does bias the process towards medical practitioners who are in favour of assisted-suicide/euthanasia and could constitute “doctor-shopping”. In the Netherlands mobile squads have been established which provide access to such medical practitioners who may never have met the patient before. Furthermore, in Oregon, there was a significant decline in people referred for psychiatric assessment over the first 5 years of legalising euthanasia/assisted suicide.<sup>26</sup> Evidence from Quebec also shows a failure of safeguards after just 2 years of legalised euthanasia/assisted suicide.<sup>27</sup>
- International evidence shows, wherever legislation is introduced to allow assisted-suicide and euthanasia, there is an incremental extension of criteria allowing euthanasia to more groups over time; including lowering the age limit – for example Belgium now allows euthanasia for minors of all ages, the inclusion of other conditions including non-terminal

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<sup>22</sup> Aaron Kheriaty, *The dangerous contagious effect of assisted suicide laws*. Washington Post, November 20, 2015. Also: Margaret Somerville, *The Importance of Stories in the Euthanasia Debate: the risks and harms to vulnerable people outweigh any possible benefits*.

<https://www.mercatornet.com/careful/view/theimportance-of-stories-in-the-euthanasia-debate/19452>

<sup>23</sup> Ministry of Health Guidelines, *Elder Abuse and Neglect*. See [www.health.govt.nz](http://www.health.govt.nz).

<sup>24</sup> <http://www.theguardian.com/commentisfree/2015/sep/05/assisted-dying-suicide-bill-justin-welbyarchbishop-canterbury>

<sup>25</sup> See <http://dredf.org/public-policy/assisted-suicide/some-oregon-assisted-suicide-abuses-andcomplications/>

<sup>26</sup> Data retrieved from Annual Death with Dignity Reports, Year 1 – Year 17.

<https://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/ar-index.aspx>

<sup>27</sup> Aubert Martin, *Two years of euthanasia in Quebec: the facts*, 2017.

<https://www.mercatornet.com/careful/view/two-years-of-euthanasia-in-quebec-the-facts/20831>

conditions such as depression and other psychiatric conditions. Recent examples are a 20-year-old sexual abuse victim in the Netherlands,<sup>28</sup> and a 17-year-old in Belgium.<sup>29</sup> It has even been argued that euthanasia for prison detainees is permissible under Belgium law based on unbearable psychological suffering.<sup>30</sup> Also there is a gradual shift from voluntary to involuntary euthanasia, for example dementia patients. It is worth noting that in 2007, 32% of euthanasia events in Belgium occurred without request or consent.<sup>31</sup> You might say - surely good legislation can prevent this expansion. The reality is “No”! Legislation cannot stop this. Why - because if death is now seen to be a right and to be a benefit worth having - then it is a right and a benefit for all, not just for some in society. Therefore, as seen overseas, any restriction on assisted suicide is open to legal challenge and over time the numbers increase.<sup>32</sup>

6. Reporting of Assisted Suicide/Euthanasia Practice (Part 2 clause 17).

- The Bill has an inherent contradiction in that it promotes assisted suicide and euthanasia as acceptable practice and a register kept (Part 3 clause 21), yet at the same time proposes an amendment to the Births, Deaths, and Marriages regulations (part 4, clause 28) so that any death through “assisted dying” is recorded as if no assistance has occurred [Part 4 clause 28 (2xii)]. This clause would prevent an accurate assessment of assisted suicide/euthanasia events and runs the risk of “hiding” this activity.
- The best legislation in the world cannot restrict this practice. To quote Professor Theo Boer, Professor of Ethics at the University at Groningen, and for nine years a Member of a Regional Euthanasia Review Committee in the Netherlands, “the very existence of a euthanasia law turns assisted suicide from a last resort into a normal procedure - don’t make our mistake”.<sup>33</sup>

7. Effects on Medical Professionals carrying out euthanasia/assisted suicide.

- A central aspect of the Bill is to provide immunity from criminal prosecution or disciplinary action for Medical Practitioners (doctors or pharmacists) involved in hastening death (unless provable that they acted in “bad faith”).
- Throughout the Bill there is the assumption that euthanasia/assisted suicide will be administered by a medical professional (doctor). However, euthanasia/assisted suicide is not a medical issue, as seen in the fact that the Justice Select Committee is hearing submissions. Furthermore, it was noted in the Health Select Committee report, that for

<sup>28</sup> Simone Mitchell Euthanasia debate reignited by 20yo sexual abuse victim. Monday May 16, 2016.

[http://www.nzherald.co.nz/lifestyle/news/article.cfm?c\\_id=6&objectid=11639637](http://www.nzherald.co.nz/lifestyle/news/article.cfm?c_id=6&objectid=11639637)

<sup>29</sup> <http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-grantedbelgium/7855620>

<sup>30</sup> Katrien Devolder, (2016). *Euthanasia for Detainees in Belgium*. Cambridge quarterly of healthcare ethics : CQ the international journal of healthcare ethics committees. 25. 384-394. 10.1017/S0963180116000037.

<sup>31</sup> <http://www.alexschadenberg.blogspot.ca/2013/09/euthanasia-is-out-of-control-in-belgium.html>

<sup>32</sup> The Netherlands saw a 190% increase in euthanasia from 2006-2015. In the 10 years to 2013, the number of euthanasia cases in Belgium has risen from about 1,000 to 8,752, according to official records.

<http://www.abc.net.au/news/2016-09-18/euthanasia-17-year-old-first-minor-to-be-granted-belgium/7855620>

<sup>33</sup> <http://www.dailymail.co.uk/news/article-2686711/Dont-make-mistake-As-assisted-suicide-bill-goes-Lords-Dutch-regulator-backed-euthanasia-warns-Britain-leads-mass-killing.html#ixzz475CQjW5M>. See: Boer, T. Rushing toward death? Assisted dying in the Netherlands, March 28 (2016) at <http://www.christiancentury.org/article/2016-03/rushing-toward-death>. Also see Theo Boer, I supported our

euthanasia law, but I was terribly wrong: Dutch ethicist. <https://www.lifesitenews.com/opinion/i-supportedour-euthanasia-law-but-i-was-terribly-wrong-dutch-ethicist>

the NZ Medical Association and the World Medical Association, “assisted dying is incompatible with medical ethics”.<sup>34</sup> The concluding statement of the Gillett report for the New Zealand Medical association, summarises the caution that is needed in bringing about a legalisation of euthanasia/assisted suicide.<sup>35</sup>

*The debate about the legalisation of euthanasia is complex and the medical profession should remain cautious about any change in law that would interfere with principles that have guided medicine and general healthcare to good effect for most people throughout the centuries. The WMA’s resolutions on euthanasia and physician-assisted suicide reflect this tradition; its clear opposition—to what would mark a departure and move towards a different ethos in an area where medical practice needs sound guidance and standards—is worthy of support because of the value it puts on human life. This stance does not prevent a physician from respecting the desire of a patient (or the patient’s guardian) to allow the natural process of death to follow its course in the terminal phase of sickness (where that may involve the withdrawal of life-prolonging treatment or treatment limitation because the treatment is properly deemed futile).*

- EAS effects on families and people involved. In countries where euthanasia/assisted suicide is legal, there is a web of people involved in each individual case – doctors, nurses, pharmacists, psychiatrists/psychologists, and often decisions of family members. We note that the proposed bill does not name nurses amongst “medical practitioners” for whom the bill provides legal protection. Also, overseas studies identify that those involved can and do suffer vicarious trauma from being involved in euthanasia/assisted suicide practices, as this quote from a study undertaken in Finland suggests:<sup>36</sup>

*We can’t go that far and have this or that kind of criteria to let you kill another person. Nobody can cope with it mentally for very long. You have to think about the personnel. Everybody’s talking about the patient but nobody says anything about the one who has to do it and who also has feelings.*

- There is an assumption that doctors will be the ones to enact any law change. But doctors see their calling as maintaining life, not taking life. Any law change would have widespread and deepening repercussions for the way we understand life, and the callings and duties of the medical profession. These are fundamental roles within society charged with caring, healing, curing wherever possible. At our most vulnerable times – when we face death - physicians (and others) have a considerable role in the care of people through a relationship in which the real questions are addressed with patient and family, unnecessary treatment is stopped or not started, relief is provided for physical, mental and spiritual distress, and the person who is dying is supported to the end. The intention is a dignified, pain-free, natural death. Euthanasia/assisted suicide and would

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<sup>34</sup> Health Select Committee, *Petition 2014/18 of Hon Maryan Street and 8,974 others*. Wellington: NZ Parliament, 2017, pg 34. [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24)

<sup>35</sup> Grant Gillett. *A Report on Euthanasia for the NZMA*, 2017, pg 64. <https://www.nzdoctor.co.nz/sites/default/files/2017-11/NZMA-euthanasia-Gillett-report.pdf>.

<sup>36</sup> Kuuppelomäki, M. (2000). *Attitudes of cancer patients, their family members and health professionals toward active euthanasia*. *European Journal of Cancer Care*, vol, 9: pgs 16–21. doi:10.1046/j.1365-2354.2000.00184.x. Also see <https://healingrefuge.com/life-issues/compassion-fatigue-and-vicarioustrauma/>. Fiona Cocker and Nerida Joss, *Compassion Fatigue among Healthcare, Emergency and Community Service Workers: A Systematic Review*. *Int J Environ Res Public Health*. 2016 Jun; 13(6): 618. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4924075/>

cut across this trusted relationship. There may also be pressures for doctor to conform to the wishes of families or patients. As Margaret Somerville suggests;<sup>37</sup>

*We also need to consider how the legalisation of euthanasia could affect the profession of medicine and its practitioners. Euthanasia takes both beyond their fundamental roles of caring, healing and curing whenever possible. It involves them, no matter how compassionate their motives, in the infliction of death on those for whom they provide care and treatment. Euthanasia thus places the soul of medicine itself on trial. We thus need to be concerned about the impact that legalisation would have on the institution of medicine - not only in the interests of protecting it for its own sake, but also because of the harm to society that damage to the profession would cause.*

8. Addressing issues preceding a request for EAS.

Rather than promoting euthanasia or assisted suicide as a 'compassionate' solution to unbearable suffering, critical factors that precede the requests could make a great difference to many more people and have a positive effect on society. These include:

- Palliative care services – improve access so all in this situation can receive care, as it has been shown that recipients of these services find hope and relief of suffering;
- Mental health services – improve access to services, provide training for recognition and treatment of depression which is frequently a significant factor in a patient's suffering and request for EAS;
- Continue/enhance programmes to prevent suicide among all age groups and reduce its normalisation;
- Address social isolation particularly among elderly people – this has been shown to be a cause of depression, and of the sense of being a burden;
- Continue measures to address and prevent elder abuse
- Providing funding and adequate resources so that society can support those in need at their most vulnerable times.

## Does a right to assisted death entail a responsibility on others to kill?

Archbishop Rowan Williams | Thursday 20th January 2005

**An article for The Times on euthanasia and assisted dying legislation.**

In the passionate argument about euthanasia and the law, the thing most immediate to many – perhaps most – people's minds is the extreme nature of the human suffering for which euthanasia is claimed as the best and most compassionate solution. It is not unfamiliar territory for those who oppose euthanasia on religious grounds. The continuing and costly investment of many religious bodies in palliative care, as well as the day to day experience of the priest or pastor alongside the dying, means that they know as well as anyone what sort of circumstances are being discussed.

Yet there are other factors at work in this argument. Ten years ago, an American court ruled that a terminally ill adult possessed a "constitutionally guaranteed right" to receive medical assistance in ending their life. Interestingly, the court cited discussion about the abortion debate in support, treating the question of assisted dying as a similar example of decisions affecting "personal dignity and autonomy" which the law should make possible.

The ruling was overturned finally. But the language was revealing. Religious opposition to the possibility of medically assisted dying is often seen simply as blind adherence to an absolute

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<sup>37</sup> Margaret Somerville, *What would we lose by legalising euthanasia?*. ABC Religion and Ethics, May 2013. <http://www.abc.net.au/religion/articles/2013/05/24/3766685.htm>.

prohibition on killing, insensitive to the obvious requirements of compassion. In this connection, though, religious opposition appears also as deaf to the appeal to a basic right, the freedom to enjoy the maximum control over your circumstances.

Thinking about the issue in relation to arguments over rights may help us to see more clearly some of the pitfalls. Do I have a right to die? Religious believers answer for themselves that they do not. For a believer to say, "The time could come when I find myself in a situation that has no meaning, and I reserve the right to end my life in such a situation," would be to say that there is some aspect of human life where God cannot break through. It would be to say that when I as an individual can no longer give meaning to my life, it has no value, and human dignity is best served by ending it.

That would be in the eyes of most traditional believers, Christian or otherwise, an admission that faith had failed. It would imply that life at a certain level of suffering or incapacity simply could no longer be lived in relation to God.

Now it is obviously true that for someone who does not share any such belief there is bound to be a different set of values at work. Why should religious people seek to impose their views by holding back a change in the law that respects a significant right and takes wholly seriously the gravity of suffering that can't be remedied or alleviated?

Apart from the obvious answer that no one is seeking to impose anything, simply to persuade legislators in a continuing debate, there is a serious point to register here that does not concern religious believers alone. The religious attitude I have described is a much sharpened acknowledgement of something that everyone, religious or not, needs to reflect about, but which is badly obscured by the language of individual "rights".

What anyone's life means is not exclusively their own affair. He lives in relation – to others and to a society. At the simplest level, what often most shocks and grieves people who have been close to a suicide is the feeling that someone who has killed himself did not know what he really meant to his friends or family, did not know he was loved and valued. And even when someone who contemplates suicide is confident that he has no friends or families to hurt, we can hardly say that his life is without significance just because he says so; the society he lives in has a view about the worth of human life which can not be mortgaged to how any individual feels.

This argument begins to bite in the present debate because assisted dying involves others in an act of suicide. Someone else has to accept your decision that prolonged life could have no meaning, and to act on that decision. We rightly talk a good deal about the dangers of the elderly and dying being pressurised by relatives or hospitals to take a quick way out that is convenient for others. What about the pressure a sick person who is determined to die places on those around them?

Rights create responsibilities, we often like to say. Does the recognition of a legal right to assisted dying entail a responsibility on others to kill? This is not an academic question. What legal implications could arise around the deliberate frustration of someone's legally secured rights, if relatives or physicians refused to act? And even if it were a matter of complete consent between patient, family and physicians, we should have given legal sanction to the assumption that the meaning of a life is no more than what an individual or a group of individuals decides to give it - an assumption that has wide repercussions for law and culture. The appeal to our sense of compassion in order to justify a change in our legal practice is wholly understandable; but could it end up undermining just that broad sense of unconditional human worth and value in which compassion itself is grounded?

Euthanasia is best defined as the initiating of a process whose explicit primary aim is to end life. It is not the same as continuing a medical process whose long-term effect may be to reduce the span of life, nor is it the same as embarking on a treatment that offers short-term relief at the cost of

possibly accelerating overall decline. These are the commonplaces of palliative medicine. The right to be spared avoidable pain is beyond debate - as is the right to say yes or no to certain treatments in the knowledge of factors such as these. But once that has mutated into a right to expect assistance in dying, the responsibility of others is involved, as is the whole question of what society is saying about life and its possible meanings. Legislation ignores these issues to its cost.

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## End of Life Choice Bill: Anglican Bishops' Submission Against

Justice Select Committee

Submission from the Anglican Bishops of Dunedin, Christchurch, Te Waipounamu, Nelson, Wellington, Waiapu, Waikato & Taranaki, and Auckland

19 February 2018

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We would like to make an oral submission.

**The submitters** As bishops of the Anglican Church in Aotearoa New Zealand, we speak out of our extensive experience in the pastoral care of the dying and their families over many years. We recognise the deep personal stress of those involved with end of life events, and seek to blend compassion with the well-being of the community, of individual rights with the common good.

**Bicultural Perspective** We are concerned that the Bill as currently drafted does not take account of the cultural, spiritual or tikanga concerns of Maori and Pasifika peoples and would wish to be heard on these matters as part of an oral presentation to the select committee.

**Summary** While recognising the great distress of patients, families and friends in the case of some intractable and prolonged terminal illnesses, it is our view that legalising medically- assisted dying will open the gateway to many foreseen and unforeseen consequences which will be damaging to individuals and the social fabric. **We recommend** that no change be made in the existing law, but that resources to enhance palliative care and counselling support for both patients and their whanau be increased.

**Comment on Preamble to the Bill** We believe the Preamble to the Bill makes at least two incorrect claims:

1. "Strong public support" for a law change is claimed on p2 of the Preamble. While it is true that public polls consistently show that a majority of the public support a law change, the quality and usefulness of these polls may be legitimately questioned. The issue is a very complex one, as noted by Justice David Collins in his ruling on the high profile Lecretia Seales' case. Polls generally ask one very simple question that fails to capture such complexity.

A recent Curia Market Research public poll indicates confusion about the meaning of 'assisted dying', with respondents thinking it included turning off life support (85%) and 'do not resuscitate' instructions (79%).<sup>38</sup>

Of the 21,000 submissions to the Health Select Committee following the 2015 Maryan Street petition, almost 80% of the submitters opposed any change in the law, and the Select

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<sup>38</sup> <https://www.euthanasiadebate.org.nz/poll-widespread-confusion-about-assisted-dying//>

Committee was unable to make a recommendation. One needs to distinguish between a popular reaction to a high profile case and the more considered submissions of experts and relevant associations who made submissions.

2. "Analysis of overseas jurisdictions where assisted dying is permitted demonstrates that concerns, including concerns about abuse of the vulnerable, have not materialised and that risks can be properly managed through appropriate legislative safeguards" (p2). This is a contestable claim and official evidence from Belgium, the Netherlands and Switzerland show that there is slippage in the criteria, the addition of new criteria, and an oversight of cases that is by no means robust.

**Moral Principle** In our view the protection of human life is a fundamental cornerstone of society, and one that is affirmed universally whether as a result of religious conviction or from other code of ethics. Every person and every life is of worth, and to legalise medically assisted dying is to undermine this moral cornerstone and open the way to damaging outcomes (see *The Dangers*, p2).

In particular there would be a significant shift in an individual's trust in the positive support of official, professional, social and family networks. Trust in the life-supporting intentions of one's human environment is replaced by a fear that systems and individuals may be planning to terminate one's life. Trust would be destroyed, and insecurity and anxiety would set in. This could happen even with members of one's own family.

Morality pertains not just to the stated criteria but also to the reality of slippage, extension of the accepted criteria and in the oversight of cases. The reality of doctor-shopping to find someone willing to sign the forms would be an obvious consequence.

**Hard Cases** Over many years of pastoral care we have experienced how distressing and prolonged a terminal illness can be. We have experienced it with our own family members. Pain, dementia, and the indignities of failing bodily functions can be extremely distressing. We do not in any way subscribe to rigid moral principles that override human compassion and care.

We are not clinicians, but colleagues in the medical profession, and especially in palliative care, advise that new technologies and drugs can do much to alleviate most pain. An Australian doctor, Karen Hitchcock, who has worked for 12 years in large public hospitals, caring for hundreds of dying patients, says she has often had patients say they want to die, but... "it is rarely because of pain, but often because of despair, loneliness, grief, the feeling of worthlessness, meaninglessness or being a burden. I have never seen a patient whose physical suffering was untreatable".

**Not Prolonging Life** We accept the wide-spread practice accepted in the medical profession of withdrawing life support systems in cases where a patient has slipped into a coma or long-term unconsciousness, there is no future prospect of recovery and the person would die naturally without the support of mechanical devices. Artificial prolongation of life in such circumstances is contrary to the natural order of dying, and not necessary. Such a step would be a decision reached by doctors and family, and may be in line with the expressed advance intention of the patient through a Living Will.

Likewise we accept that the provision of morphine or other drug for the purpose of pain relief is both acceptable and desirable, even although one of the side effects may be the shortening of a person's life. The latter is not the intention and hence this widely established form of medical care to relieve pain is an important part of palliative treatment.

**The Dangers of Legislative Change** We believe the legalising of medically-assisted dying, while intending to assist in hard cases, could open the way for many unfortunate outcomes:



1. The creating of a legal option establishes medically assisted dying as an acceptable and socially approved form of ending life which could encourage its use.
2. Instead of being restricted to intractable cases of terminal illness, categories might extend to include other forms of treatable illness, depression, loneliness, the handicapped or babies born with severe deformities. Many suffering such conditions, or their parents or guardians, might take advantage of a new way out of the situation. Evidence from Belgium, the Netherlands and Switzerland indicate such realities.
3. Official committees set up to approve applications might in time adopt a de facto “death on demand” ethos, turning down only a few applications. Again, evidence from European nations suggests a lack of robust oversight.
4. Elder abuse is a well-established reality of our society and increasing year on year. Family members and care providers might bring subtle, or not so subtle, pressure to bear on an ageing family member to “do the decent thing” and exit this life. We have known situations of such pressure driven by family members alarmed to see their inheritance evaporating with the costs of caring for an ageing parent.
5. Ageing family members themselves may feel the guilt of being a burden on their families, or they may see long-term friends taking the step and feel pressured to do the same.
6. In times of budget constraints, governments or health boards may see medically-assisted dying as a way of saving on the health budget and reduce funds for aged care.
7. This could lead to a restriction of resources for palliative care, quality aged care, or providing social support for the lonely or depressed.
8. Bicultural issues and the Treaty of Waitangi come into play insofar as the concept of whanau for many Maori makes caring for the extended family in all circumstances a priority. We need to take care that a majority of public opinion does not over-ride the culture of a Treaty partner.
9. Suicide: It is ironic that in a country plagued by the most disturbing increases in suicides, especially among impressionable youth, we are contemplating assisting people to die. The pain of a teenager, young adult or, for that matter, a person of any age who seeks suicide as a way to die, is viewed as tragic. Frequently it is said that the family and loved ones never fully recover. Yet the pain of a terminally ill cancer patient is viewed as worthy of consideration as a candidate for assisted dying. On what basis do we understand the difference? It is worth noting in Belgium a depressed patient is a candidate for medically assisted dying. This is not because this depression is terminal but because it is viewed as incurable, (and this appears to be a development or extension of the original legislation). This seems so at odds with the virtue of hope and the value we place on life. Followers of Jesus Christ and members of other world religions hold to the teaching of the sanctity of life. Life is a gift to be treasured and thus to assist death is misdirected action and a devaluing of death.

To assist dying is not the same as increasing pain medication which may or may not eventually shorten the life of the patient. One seeks death. The other seeks quality of life. There is a significant difference. The difference in intention is very marked. In our own pastoral experience we know how families and loved ones may be painfully divided as a result of disagreements over assisted dying.

10. Coercion of the Medical Team and Family: To place a cost on medical care and social care and then evaluate the reasonableness of assisting dying places a price tag on human life. Human persons are relational and devaluing any one human being’s life affects the larger community. To say that one human life is expendable is actually to state the quality of community is insufficient to support people in their last months. Indeed, in Belgium there

are instances of medically assisted dying when there is every reason to expect longevity without such intervention. Yet medically assisted dying is permitted.

We live in a society that insists and encourages ramps and assistance for those who have physical disabilities because we recognise them as members of the community and we want to offer inclusion. In return we find we benefit from their participation and inclusion. How odd therefore that we are moving towards saying we have neither the will nor the means to keep other people alive, comfortable and included. There is a time-honoured question among people about how does a government, a community or a family define and assure free choice among the members of the population? One also might ask when in history has hastening death, even by choice and with great consideration, ever improved community well-being?

11. Palliative Care and Hospice Care: It is frequently commented that Palliative Care units and Hospice Care ministries are places of extraordinary hope. However these remarkable places and ministries are already underfunded and at present there are inadequate research funds supporting their progress. Why would we ignore or overlook such effective services and seek instead to fund medically assisted dying?

Emotions and fear will always fuel and drive this argument from every side and we want to acknowledge there are people of good will on every side of the debate and recognise the importance and validity of emotion in the decision-making process.

We are conscious of how Megan's Law in the USA (and similar legislation in the UK) was seen to be hurried into practice on the wave of a huge emotional reaction to the abuse and death of a child. Without denying the horror of the circumstances, it has been said that a more dispassionate response may have generated a better piece of legislation.

When the balance is examined, we believe the prospect of this practice, of medically assisted suicide, passing into law, carries far more risk for harm for individuals and community life, than does the improvement and support of palliative and hospice care. Human beings are not disposable. In the words of Dame Cecily Saunders: "You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die."

Our experience is that there are individuals who believe their worth has always been in being useful to others. When they are no longer useful and helpful for the common good, they may feel it is time to get out of the way. But this person is still to be valued and cherished. They still make a contribution by allowing another person to sit with them, keep watch and hold their hand. The person remains valuable and valued in the sight of God; their loved ones and the larger community. Please do not write them off.

Looking more closely at the opinion polls suggesting a big majority in New Zealand in favour of an Assisted Dying Bill, it is difficult to know what it is that New Zealanders are wanting to change. Is it wanting to reduce the incidence and extent of pain, nausea, vomiting, breathlessness – or any of the symptoms that can be controlled medically; or is there really a call to allow the intentional ending of a life? And would a measure that allowed one individual to end the life of another – even with safeguards – actually fulfil the sincerely held views aspiring to a peaceful death?

**Conclusion** We acknowledge the tensions in this very difficult debate on how to maintain the principle of the worth of each individual along with adequate care for those in stressful situations. Our view is of an "on balance" nature weighing up the pros and cons of the options. We therefore believe:

1. New Zealand should not enact legislation that would establish medically-assisted dying as an authorised form of terminating life, thus undermining a fundamental ethical principle.
2. We should take steps to increase resources for palliative care, and the provision of social support for the lonely, ageing and depressed.
3. We should enhance support for families caring for those with terminal illnesses to assist them in understanding what is happening and likely to happen, how to manage stress and grief, and how to build positive relationships with the dying, remembering that dying can be an important last phase of life in resolving conflicts of the past and establishing new relationships of love and care.

## Three bishops support EOLC Bill

BISHOP JIM WHITE | 26 FEB 2018 | TAONGA<sup>39</sup>

### Dying To Live

We speak as bishops of the Anglican Church in support of assisted dying. We are aware that most of our colleagues don't agree with our position, but want to testify that there is a wide diversity of views on assisted dying in our churches. We believe that for some individuals with a terminal illness, assisted dying can be a good and moral choice and that we should offer medically competent assistance in carrying out such a choice.

Our own views are shaped by pastoral experience with dying people and wanting to honour their consistent desire to remain in charge of their lives and dignity for as long as possible. The current law supports that desire very unevenly. While we would wish along with Hospice NZ that this debate should only happen when everyone enjoys access to quality palliative care, we see little evidence of that arriving soon. In the meantime, many are forced to suffer unnecessarily and we join our voices to many in this land who desire an amount of sensible change in our laws. It is a deeply unfortunate fact that for some the "right to life" is translating into a duty for them to go on suffering and this has to end.

We are well aware that everything depends on your starting points in this debate. It does not matter whether your moral framework is utilitarian, Kantian, Virtue theory, or 'bible based,' there are counter arguments from the same framework. Most arguments circle back with warnings about where a change in legislation might lead, threatening risk of abuse of the elderly, people with disabilities and other vulnerable groups. These "slippery slope" arguments have endlessly dominated the euthanasia debate, much of it driven by fears of the notorious Nazi Action T4 campaign to eliminate "undesirable groups", miss named "euthanasia." Firstly, there is a mile-wide distinction between the murder by authorities for purposes of racial purity and political expediency and laws that allow assisted dying by those who choose for themselves to shorten their life in the face of a terminal illness.

Secondly, we have yet to find convincing evidence, especially evidence that is devoid of layers of interpretive bias, that legally available assisted dying has created the much feared slippery-slopes. We would want any changes in our laws to be accompanied by a rigorous and independent monitoring body.

Our starting point is not a warning but an affirmation of the dignity and autonomy of every individual. We take an individual's capacity to decide how to live life fully to be of the highest value. We want to be sure each individual has a responsibility to make choices with respect for the well-being of others, in honest conversation with friends and family, and, from our perspective,

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<sup>39</sup> [http://www.anglicantaonga.org.nz/features/extra/3\\_eolc](http://www.anglicantaonga.org.nz/features/extra/3_eolc)

prayerfully. We believe that when a life is ending with unbearable suffering and great indignity, the individual concerned should be able to seek assistance in dying with dignity and mercy for all involved.

We acknowledge that many in this debate are feeling fearful. Our experience is that some of those we have been alongside have been desperate to end their lives (or have help to end their life) and have got to that point carefully and prayerfully. So, often such a decision has seemed without fear but, in fact, full of courage.

We know that fear is contagious and does not help us make good decisions. However, we would like to note that many in our society are fearful of ongoing treatment. They don't want to end their days in a hospital bed with no sense of the things that they value around them. Of course, those resisting a law change would say that no one has treatment without consent, but in our experience people are often fearful that they will be coerced or find themselves caught up on an exorable treatment treadmill.

We might actually be fearful that if our law does not change, at least in some measure as we would hope, that people will increasingly choose to end their lives prematurely (and before they are in any way disabled by disease or illness) by the many methods that are suggested on the internet.

So, we enter this debate by placing the highest value on the capacity to exercise autonomy over one's own life. If that is where we begin, then it has a major effect on balancing the likely outcomes and risks of a change of law. We recognise that any new law for Aotearoa New Zealand would affect different cultures in different ways and we don't pretend to speak for Maori in particular, well aware of their history of being written off as a "dying race". A law change need not have any coercive or prescriptive effect on any who don't choose to exercise the right to assisted dying, heavily qualified as it should be.

The primary qualification in our view is that assistance in dying needs to be confined to those with a terminal illness as set out in the legislation. We do not support the additional ground of "unbearable suffering" and believe that would lead us into a tangle of self-defined exemptions and dangerous precedents. The new legislation in the state of Victoria sets a useful model (and one close to home) and gives us a conservative (terminal illness only model) and comparison to begin what will no doubt be an evolving pattern of legislative reform as we learn from experience.

The experience of other countries is valuable for studying the consequences and unintended effects of assisted dying laws, now available in four European countries, Canada, Columbia, Victoria (Aus) from this year, Oregon for the last 20 years, and other states, making it available now to one in six Americans. The slippery slope effects of law changes don't seem to have happened, and the actual use of drugs to end life, even when prescribed, are often not taken.

Assisted dying legislation in New Zealand would not come as something new. A de facto practice has long existed and been accepted, even praised in extreme situations. The medical practitioner who administered a fatal dose of morphine to a person trapped in the wreckage of the 1931 Napier earthquake is famous but only one of many such stories. In clinical situations the line between active and passive assisted dying is thin and moveable, and the decision to withhold treatment that would prolong life is frequently made. Very often the terminally ill person has only been able to continue living through medical intervention and the right to stop those interventions must lie with the patient. In the U.K. in 2006-8 18.5% of all deaths resulted from palliative sedation.

The new law would bring some clarity to what is often currently an ad hoc and subjective process of decision making, leaving doctors and nurses legally vulnerable, and forcing those dying to consider improvised and grotesque ways of dying that leave loved ones traumatised.

We end this submission where we began, namely with the dignity and autonomy of every individual to make choices and take responsibility for their life. We respect that autonomy by legally permitting abortion, the right to deny permission for surgery and medication, the freedom to indulge in life threatening sports and adventures, to risk and sacrifice life in the armed service of country. These choices are properly available throughout our lives but denied at the end, for reasons that have more to do with fear than trust in each other.

We believe the country is ready to deal with a change in the law. Informed estimates from medical practitioners suggest that about half our doctors and 70% of our nurses would agree, as well as a majority of the New Zealand public.

As New Zealanders who affirm that all life is sacred, and who follow a God who is all about ending suffering rather than intending it, or insisting it must always be endured, we don't believe a change to the law would contradict that sanctity or offend that God.

Bishop Jim White

Bishop John Bluck

Bishop David Coles

## Audio Recordings: Assorted Interviews

### Why I changed my mind: Lord Carey

Lord Carey, BBC Interview : <https://www.bbc.co.uk/sounds/play/b098jy5f>

Dominic Lawson asks former Archbishop of Canterbury George Carey why he changed his mind from opposition to any euthanasia to support for assisted dying to be made legal in the UK.

A lifelong opponent of euthanasia, George Carey recently changed his mind on an issue which the Church of England has always opposed - assisted dying for those who can decide for themselves that their suffering as a result of very serious medical problems is too much to bear. He explains how he decided to change his views on such a significant issue for the Church.

In "Why I Changed My Mind", Dominic Lawson interviews people who have changed their mind on controversial matters.

Producer: Jonathan Brunert.

### Jean Vanier, founder of L'Arche, urges caution on doctor-assisted dying law

<https://www.cbc.ca/radio/asithappens/as-it-happens-tuesday-edition-1.3609214/jean-vanier-founder-of-l-arche-urges-caution-on-doctor-assisted-dying-law-1.3609219>

## Euthanasia means 'good death', not 'quick exit'

International Conference for Ageing and Spirituality, Auckland, 2 September 2009

Bishop Richard Randerson

In his recent book "Before We Say Goodbye", Sean Davison provides a very moving and sensitively written diary of the last three months he spent with his late mother, Pat, leading up to her death in Dunedin in 2006. Terminal illness is a situation known sooner or later to us all, whether personally or within the whanau of family and friends. There are very stressful situations, and no easy answers.

My mother died at age 90, frail, unable to communicate or do anything for herself. Although she did not contract pneumonia, our family was asked if in such a circumstance we would want the

hospital to administer antibiotics, or keep her comfortable. We chose the latter. The question of euthanasia which such situations raise is a fraught one which most of us wrestle with personally. There is no simple answer, no hard-line ideological prescription.

I start from three principles:

1. Life should start, proceed and end as naturally as possible
2. With the aid of medicine and technology, we should take steps to maximise human wellbeing and minimise those factors that work against human wellbeing.
3. In the spiritual domain, we should facilitate the growth of a deeper sense of oneness with one's God (however defined), and the peace of mind and soul that comes with that.

In the case of someone in a terminal situation (which I know raises questions of definition of its own), I would define human well-being as:

4. Minimising pain and distress
5. Maximising the opportunity for human relationships, especially with those close to us, and promoting spiritual wellbeing.

The conclusions I draw from this with regard to those who are terminally ill are:

6. I see it as a matter of the patient's advance directives as to whether steps should be taken to artificially prolong life if in a terminal condition e.g. providing antibiotics to combat pneumonia, resuscitating someone after heart attack or stroke, or continuing with life support systems. The advance directives may be established by a Living Will or other statement of intent. For some in the medical profession, prolonging life may be seen as a question of professional pride.
7. The medical profession should use any medical means at their disposal to relieve pain and distress, and make the patient comfortable. If in the process this shortens the person's life, that is acceptable insofar as the intention is the relief of pain and distress. Again, I am aware that effective means of achieving this, e.g. by the use of morphine, are complex.
8. I am uncomfortable with any intervention to extinguish a person's life as a direct act by, for example, the injection or ingestion of chemicals having a lethal consequence. To me this has the feeling of an execution, and contravenes the principle of allowing life to end as naturally as possible (see 1 above).

Euthanasia -Greek *eu* (good) *thanatos* (death) – is in common usage the situation outlined in (8), whether death be by the hand of others, or by others assisting a person to take his/her own life. (See the final paragraph for a truer meaning of 'euthanasia'). There are several considerations here to note :

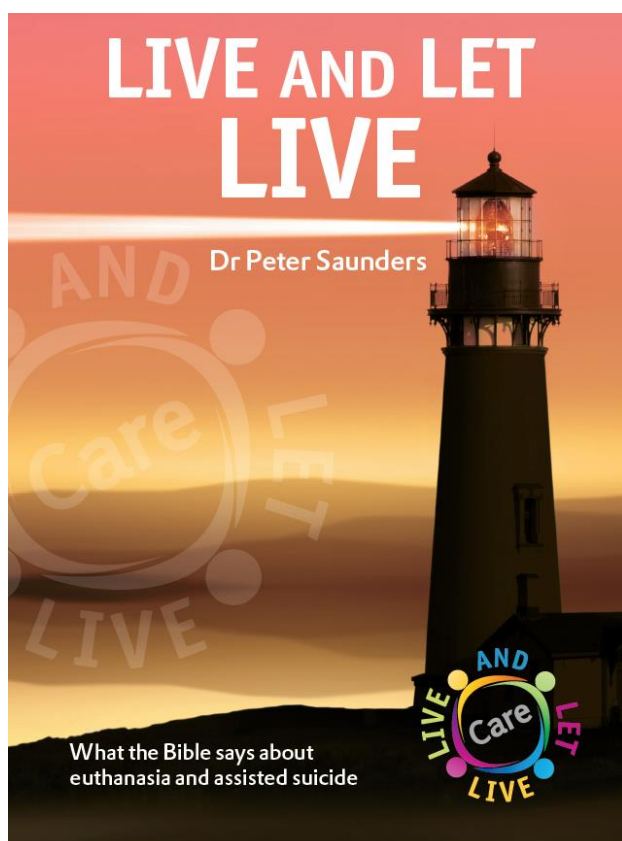
9. The period "before we say goodbye" can be rich with opportunities to deepen relationships, tie up loose ends from life, and say things we might not have the chance to otherwise say. This process is richly outlined in Sean Davison's book. The deepening of one's spiritual life can also be a central part of this process.
10. The euthanasia option could put pressure on the dying person to say "End it for me now, dear : I don't want to be a burden to you"
11. It might also lead to situations where a family conveys a message to a dying relative (even if only implicitly) : "Come on, Mum, do the decent thing".

12. The euthanasia option might be extended to people who are handicapped, depressed, or in some other situation which is not terminal, even although stressful. In such situations it is preferable to help people find new meaning and purpose in living, rather than make a quick exit.
13. The success of option 7 (making life comfortable for a dying person) is dependent on the availability of good palliative care facilities. A palliative care physician who has cared for large numbers of dying patients over many years reports never having been asked for assistance to die where effective palliative care facilities exist. But in rural areas such facilities may be slim or non-existent. This is a challenge to our health service.
14. We need to be aware of extensions of the euthanasia option. Australian euthanasia advocate, Dr Philip Nitschke, appears to favour voluntary euthanasia as a means to shorten the lives of the ailing aged as a means of reducing the fiscal burden on the nation's health budget. Nitschke writes: "So the next time you hear a government minister trying to argue why this or that payment or welfare programme for single mothers or war veterans must be cut, counter their argument with their fiscal irresponsibility on end-of-life choices." (*Killing me Softly*, p 131, 2005).

The choice is not easy. We are dealing with human life and death, pain and weakness, loving relationships that are central to our lives. On balance my view is that we need not artificially prolong life, nor terminate it by direct intervention. We should reframe our use of the word euthanasia using it not in the sense of a quick exit, but rather in its true meaning of 'a good death', one which values all life, seeks ways to make the ending of life as comfortable and pain-free as possible, while being enriched by the presence of family and friends, and the love of God.

Richard Randerson is the former Anglican Dean and Assistant Bishop of Auckland.

## Live and Let Live: Dr Peter Saunders



### Human beings are unique

The Bible teaches that human beings are unique in all Creation because they are made in the image of God:

Then God said, "Let us make humankind in our image, in our likeness, and let them rule" Genesis 1:26

It is on this basis, after the flood, that God introduces to all humankind the death penalty for murder:

"Whoever sheds the blood of man, by man shall his blood be shed, for in the image of God has God made man." Genesis 9:6-7

This prohibition against killing *legally innocent* people is later formalised in the sixth commandment:

"You shall not murder." Exodus 20:13



Care [Live and Let Live](#)

## Human life belongs to God

There is no provision in Scripture here for compassionate killing, even at the person's request, nor is there any recognition of a 'right to die' as all human life belongs to God:

*"The earth is the Lord's, and everything in it, the world, and all who live in it; for he founded it upon the seas and established it upon the waters." Psalms 24:1*

*"The Lord brings death and makes alive; he brings down to the grave and raises up." 1 Samuel 2:6*

According to the Bible then, our lives are not actually our own. Euthanasia, suicide and therefore assisted suicide are wrong.



Care **Live and Let Live**



## Euthanasia in the Bible

There are two instances of euthanasia in Scripture. In the first, Abimelech, believing himself to be fatally wounded asks his armour-bearer to kill him:

*Abimelech went to the tower and stormed it. But as he approached the entrance to the tower to set it on fire, a woman dropped an upper millstone on his head and cracked his skull. Hurriedly he called to his armour-bearer, "Draw your sword and kill me, so that they can't say, 'A woman killed him.'" So his servant ran him through, and he died. Judges 9:52-55*

In the second, an Amalekite despatches the mortally injured Saul, still alive after a failed attempt at suicide:

*"I happened to be on Mount Gilboa," the young man said, "and there was Saul, leaning on his spear, with the chariots and riders almost upon him. When he turned round and saw me, he called out to me, and I said, 'What can I do?' ... Then he said to me 'Stand over me and kill me! I am in the throes of death, but I'm still alive.'" 2 Samuel 1:6-9*

These two cases demonstrate the two main arguments people make for euthanasia and assisted suicide: autonomy – 'death with dignity' and compassion – 'release from suffering'.



Care **Live and Let Live**

## Protecting the vulnerable

The Bible repeatedly tells us to:

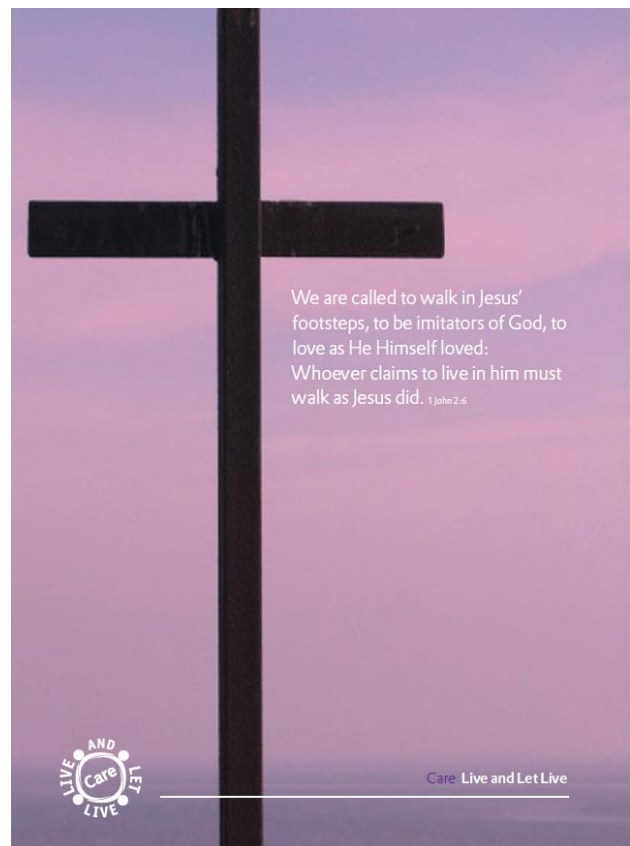
*Defend the weak and the fatherless; uphold the cause of the poor and the oppressed. Rescue the weak and the needy. Psalm 82:3,4*

In the passage below, it is made clear what is prohibited, namely the 'intentional killing of an innocent human being':

*They shed innocent blood, the blood of their sons and daughters, whom they sacrificed to the idols of Canaan, and the land was desecrated, by their blood. Psalm 106:37,38*



Care **Live and Let Live**



We are called to walk in Jesus' footsteps, to be imitators of God, to love as He Himself loved: Whoever claims to live in him must walk as Jesus did. 1 John 2:6



Care **Live and Let Live**



## Spirit of love

In the Sermon on the Mount, Jesus teaches us to go beyond the demands of the sixth commandment to fulfil the very spirit of love on which it is based:

“You have heard that it was said to the people long ago, ‘You shall not murder, and anyone who murders will be subject to judgment.’ But I tell you that anyone who is angry with a brother or sister will be subject to judgment...” *Matthew 5:21*

Rather than lead people to an untimely death, as Christians we should do all we can to nurture life, love and hope. This will involve self-sacrifice and maybe heartache for the sake of others. This attitude marks us out as God’s servants:

Be imitators of God, therefore, as dearly loved children – and live a life of love, just as Christ loved us and gave himself up for us as a fragrant offering and sacrifice to God. *Ephesians 5:1, 2*



Care Live and Let Live



- The present law making assisted suicide and euthanasia illegal is clear and right. The penalties it holds in reserve act as a strong deterrent to exploitation and abuse whilst giving discretion to prosecutors and judges in hard cases.
- In a free democratic society there are limits to human freedom and the law must not be weakened to accommodate the wishes of a small number of desperate and determined people but put others at risk.
- A far better alternative is excellent hospice and palliative care provision that meets people’s physical, social, psychological and spiritual needs.



Care Live and Let Live



## Powerful arguments

Some Christians may wonder whether occasionally there are situations in which helping someone to end their life is acceptable, especially when faced with emotive hard cases and false arguments. Even if we believe it is wrong it may be difficult to express why when asked for our opinion.

We have powerful arguments to use against the legalising of any form of euthanasia including assisted suicide.

### Euthanasia is dangerous, unnecessary and morally wrong:

- Any change in the law to allow assisted suicide would place pressure on vulnerable people. This includes those who are elderly, disabled, sick or depressed who could feel under an obligation to agree to end their lives for fear of being a financial, emotional or care burden upon others. These feelings would be greatly accentuated in a time of economic recession with families and health budgets under pressure.
- Members of the medical and health professions and disabled people’s advocates are strongly opposed because they fear the dangers associated with such a change.
- It is an accepted and established practice that sometimes treatment given purely with the purpose of alleviating suffering may result in a person dying sooner. This ‘principle of double effect’ is never thought of medically as a form of euthanasia.
- Historically – and still today – British parliaments have consistently voted against any attempt to legalise assisted dying.



Care Live and Let Live

## Christian response

We must speak up for those vulnerable people who really have no voice:

Speak up for those who cannot speak for themselves, for the rights of all who are destitute... defend the rights of the poor and needy. *Proverbs 31: 8, 9*

God calls us, as Christ’s followers, to give our whole selves to the love and service of others by expending our time, money and energy in finding compassionate solutions to human suffering:

Carry each other’s burdens, and in this way you will fulfil the law of Christ. *Galatians 6:2, 10*

This has indeed found practical shape historically in the hospice movement and in good palliative care – pioneered in large part by Christian doctors and nurses in the UK. We must work hard to make this compassionate, effective care more widely accessible.



Every year 250,000 people are helped in hospices and at home.

Help the Hospices,  
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Care Live and Let Live

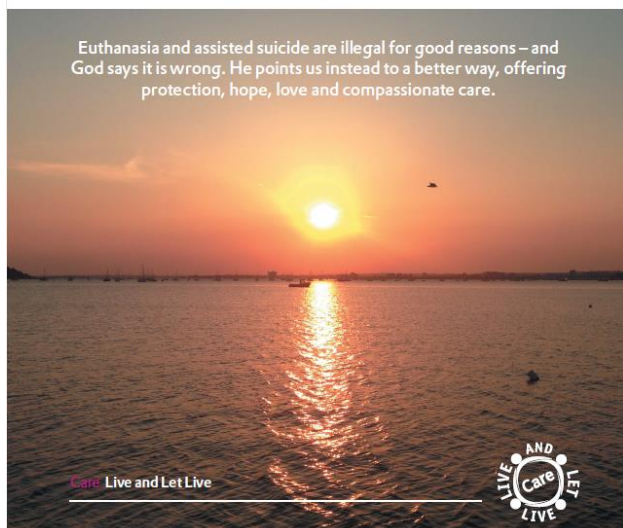
## Death is not the end

Perhaps the most powerful Christian argument against euthanasia and assisted suicide is that through Christ's death and resurrection for our sins we can look forward through the eyes of faith to a new world after death with God:

He will wipe every tear from their eyes. There will be no more death or mourning or crying or pain, for the old order of things has passed away. *Revelation 21:4*

But for those who do not know God, neither euthanasia nor assisted suicide are a 'merciful release'. It may rather be propelling them towards a judgement for which they are unprepared. It may be the worst thing we could ever do for them.

Euthanasia and assisted suicide are illegal for good reasons – and God says it is wrong. He points us instead to a better way, offering protection, hope, love and compassionate care.



Live and Let Live resources are available at  
[www.care.org.uk/liveandletlive](http://www.care.org.uk/liveandletlive)

Dr Peter Saunders is Chief Executive of Christian Medical Fellowship  
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Care Live and Let Live

## Newspaper Articles and Ethical Positions

### Assisted dying is an ethical minefield and not just a matter of personal choice

Daily Telegraph, Charles Moore, 9 FEBRUARY 2019 • 6:00AM

On Thursday, Geoffrey Whaley took his own life in the Dignitas clinic in Switzerland. He was 80, and suffering from motor-neurone disease which had made him physically almost completely helpless. In a letter to Members of Parliament, published posthumously, Mr Whaley spoke of the “anguish” which he and his wife Ann had suffered last week because, after an anonymous tip-off, police had interviewed her under caution. They feared she might be breaking the law which forbids helping someone commit suicide. According to press reports, the police have since dropped the case. Mr Whaley’s dying wish – the reason he wrote specifically to MPs – is for there to be a change in the law.

Mr Whaley’s story follows a familiar media pattern. It is one of a determined and suffering person, usually with a brave and supportive spouse and/or children, making a rational choice to die rather than suffer further. In this narrative, any public authority which tries to block the path is shown as cruel and, to use a word chosen by Mr Whaley, “hypocritical”: it is possible to make arrangements to end your own life abroad but illegal to get anyone here in Britain to help you.

Such stories deserve to be told, and carefully heard. Because of journalism’s love of a “human interest” story, they carry all before them in emotional terms. The comment pieces which follow overwhelmingly take the side of the protagonists and attack the state of the law. These stories are

powerful. They badly lack something, however, which those who make our laws are duty-bound to consider: the wider context.

MPs must (and do) think about the effect not only on the relatively few who decide to go to places like Dignitas, but also on everyone else, especially the vulnerable. It is not out of stupidity that Parliament has repeatedly, after much debate, declined to change the law in the way Mr Whaley demands. It is because this is a profoundly difficult subject.

In media terms, it is much harder to tell the story of those who have not sought the path of assisted suicide than that of those who have; yet there are hundreds of thousands – perhaps millions – of the former. They vastly outnumber the latter.

Those who favour assisted dying tend to present the wish to commit suicide in the face of dreadful illness as almost unarguably logical. Last month, I received an email from a member of the organisation, Dignity in Dying. The gentleman suffers from multiple myeloma, a fatal bone cancer. “There is living and there is being alive,” he says, “I want to be living, I cannot contemplate lying in a bed, in pain, covered with a blanket, slowly deteriorating and waiting to die, how awful, how cruel, is that?” He points out how different “your belief and value system can become” when you are in this plight.

I am sure my correspondent is giving an accurate, heartfelt account of many people’s feelings, but I also know that not all sufferers feel this way. Three years ago this very day, my wife’s younger brother died of myeloma, aged 55. It is indeed a most cruel disease, in his case made even worse by original misdiagnosis. During his illness, he lived for more than four years next door to us. We used to give him supper in our house every night. In all that time of closeness, he never spoke of ending his life. When asked, nearing death, if he wanted a “Do Not Resuscitate” notice in the event of incapacity, he said no.

I hesitate to mention my brother-in-law’s case, because he was the last person to wish to present his own example to prove a point. Although a man with many friends, he had a core of privacy. He was in constant pain, but the worst he would ever say of his own condition was “not so good”. Although entirely tolerant of those who thought otherwise, he had no belief in the existence of God. In soldiering on, he was not trying to uphold a religious tenet. He was simply brave and honest. This is what gave him, to coin a phrase, dignity in dying. The cancer duly killed him. It was a terrible thing to watch. But his last years of life were not worthless: they were inspiring. Nor were they unendurable: he endured them.

There are thousands of such examples every year. It is important that people hear about them. Otherwise, those facing terminal illness will receive only a message of despair. Despair is false – as false as false hope.

At this point, supporters of assisted dying will object – correctly – that they are not advocating assisted dying for all. They want it accepted only as a legitimate choice. But here we come to the question of the effects on others.

I often wonder what I would do if someone dear to me asked me to help him or her commit suicide. Of course I cannot answer confidently, but I do know I would feel in an impossible position. Your desire to do what the person you love badly wants directly conflicts with that love. The present law helps make that conflict less likely.

I also notice that when a person does kill himself, even with the full support of a spouse or child, a great wound is inflicted upon those left behind. It works its way very slowly through the mind, as shrapnel in the First World War worked through the body. How much more must this be so if you positively helped the person you loved to commit suicide.

In an interview shortly before he killed himself, Mr Whaley was asked if he was worried about the consequences of a possible police inquiry for his wife of 52 years. “No,” he said, “what’s the point of worrying about things you can’t do anything about?” But he could have done something about it if he had decided to live.

In this era, personal choice is supposed to conquer everything else. Yet no man is an island. His choice affects others. This turns out to be true even – indeed particularly – in death, the most isolated of human experiences.

If the assisted suicide choice becomes law, what of the vulnerable? The cases brought to our attention by Dignity in Dying tend to be those of strong-minded, well-supported people. Sadly, this is untypical of those in extremis. As the pains and fears of death approach, many are confused, often suffering from the side-effects of drugs, often weakening in the mind. Are they really helped by the god of autonomous choice as they face the one fact which offers no ultimate choice?

One must not forget that not everyone is enlightened about the vulnerable. A good many people believe in a sort of social hygiene. They see the lives of weak groups like the old, destitute, mad, mentally handicapped, autistic, disabled or the terminally ill as pointless. As well as them are the much smaller but not insignificant numbers who wish harm to their next of kin because they want their money or are simply fed up with them. In a public health system always short of cash, how safe would vulnerable people be if policy or financial pressures or personal malice told them to stop blocking the beds and choose to leave this life, and the law permitted professionals to help them on their way?

In this most delicate of questions, Mr Whaley’s eloquent farewell letter is by no means the last word.

## Euthanasia challenged

7 April 2017

Russell Powell

<https://sydneyanglicans.net/news/euthanasia-challenged>

Scottish theologian Professor John Swinton, who is in Australia consulting for the Hammond Care health and aged care group, has urged Christians to resist the renewed push for the introduction of assisted suicide.

Professor Swinton holds the chair in Divinity and is Professor of Practical Theology and Pastoral Care at the University of Aberdeen. He was the keynote speaker at last year’s Dementia and Faith Conference in Sydney and his recent book, *Dementia: Living in the memories of God* won him the Michael Ramsey Prize for theological writing.

His work has brought him into contact with advocates for assisted suicide. “Why is it that people say euthanasia is okay in the context of dementia?” he asks. “It has to do with the sense that you somehow lose yourself or you’re somehow not the person used to be and so, therefore, your life isn’t worth living. My experience [of] people with dementia, and also working with carer services who work alongside people with dementia, is that this is simply not the case.”

He says it is vital for sufferers to have good relationships, a good sense of spirituality, a sense of security and trust. “If you get somebody in a good solid environment you can actually live very well with dementia. There is an element of sadness and brokenness, of course, but there are also elements of positivity and hope.”

Professor Swinton says [some of] the issues raised by euthanasia proponents are “projection”.

“You encounter someone who has a disability – say, someone who has paraplegia – and you think, ‘Oh, wouldn’t it be awful if I had paraplegia?’ You imagine yourself moving from your current situation into their situation, which means it’s a story of loss and brokenness. Whereas if you speak to people with paraplegia you may get stories of loss and brokenness, but you’ll also get stories of relationship and possibilities in which you can live well within your community.

“In relation to euthanasia, you see that quite a lot of people use their imagination and project onto individuals what they think it would be like to have this particular experience and use that as a rationale for a kind of ethical argument for euthanasia. Whereas if you are living through certain things the experience is oftentimes very, very different – assuming that you have good quality of care and a solid community around you.”

Media personality Andrew Denton has used his father’s battle with heart disease as an example of why the law should allow assisted suicide. Victoria is considering a Euthanasia Bill and there will be pressure for similar legislation in NSW as early as this year.

Professor Swinton says we should learn from the experiences of countries where assisted suicide has been introduced. “They are starting to see the downside, particularly in something like dementia, because the way – as I understand – the legislation runs, basically as soon as you have a diagnosis of dementia you can, in principle, ask to be euthanised,” he says.

“This means people end up being euthanised at stages in their lives when actually they seem to be quite together. You could imagine your great-aunt Sophie, who suddenly disappears. The last thing you saw she had a diagnosis and then you don’t see her again. That’s very traumatic for families but it’s also very traumatic for doctors and medical staff who have to actually engage in these practices.”

Professor Swinton says there should be a clear Christian voice in the public discussion. “I think it is a very important thing to have on the agenda because the Christian perspective on what a human being is, what human life is and what human value is, is fundamentally important for the conversation. Whether we ‘win’ or whether we ‘lose’ is not the point. The key thing is that we must have a voice in the conversation and alternatives need to be clearly and fairly laid out.

“One of my concerns about the conversation around euthanasia is that it kind of masquerades as an ethical discussion but actually it is like a clash of worlds. A Christian perspective says human life is inherently valuable because God places value on it. Society tends to think the only thing that is valuable is choice – to live a life where you have choice, freedom and autonomy.

“So it’s not simply a matter of ethics, right and wrong. It is actually two completely different ways of looking at the world.”

## [Correspondence between Brendan Rope and Rev John Fox](#) [Human Rights slip behind animal rights](#)

Brendan Rope | Hawke’s Bay Today | 22 January 2018

It is 2018 and there is a proposed law sitting in front of the citizens of New Zealand that cuts to the very principle behind being an intelligent and compassionate species.

New Zealand is a country that has had significant leadership milestones shaping the world order in fairness and sensibilities. It seems ludicrous in this day and age that women did not have the right to vote. We stood up and gave the proverbial finger to the nuclear arms movement.

Now is the time to say enough is enough to our own obsession of prolonging life when the living is over and follow suit of other nations that have already taken the lead.

In 2014 my father was diagnosed with Motor Neurone Disease (MND). The symptoms started with slurring so initially it was thought he was partaking in a little too much of his favourite tippie, beer (a good Kiwi bloke). He quickly pointed out he was not drinking any more and actually less than he used to.

After a few doctors and specialists visits he was diagnosed with MND. As we started to understand what this meant, it was devastating. No cure. Limited time left and progressive degeneration of faculties starting with the muscles of the mouth and moving to arms, legs and other extremities. One small concession was it did not affect his mind and cognitive capacity.

He lost control his tongue and mouth and therefore his ability to speak. This was very tough for him as it decreased his ability to communicate and be involved in everyday life. He still able to gesture and write notes. As the control of his hands and feet decreased the writing stopped but he was still able to tap out a few words on a tablet but he found this difficult and frustrating.

At this point he was unable to taste, chew and therefore eat solids or enjoy food. Liquid diet before progressing to a direct feeding tube. A constant fear of choking on his own saliva. He was starting to have falls and my mother had to be with him or have someone around at all times.

He couldn't wipe his own face or rear. He had to be showered. He could not communicate other than with a nod or shake of his head or a shrug. He was trapped in a shutting down body with an inevitable end coming. His life as he wanted (and any normal human being would want) was over but he had no way out.

It was never lost on him, as a farmer for a good part of his life, that if he had an animal that was suffering the same or similar physical and psychological ordeals they would be put down. He did not have this option and he had no opportunity end of life dignity, ie going out on his terms.

There was one exception - he could refuse to "eat". When the palliative care nurses came to pour more "food" into his feeding tube he sent them away. My father starved himself to death. It was his only legal option to die with dignity.

My father's last few months were awful for him. A proud man with a fully functioning mind but a body that was shutting down. On the farm he wouldn't have let his animals suffer like he had to.

This has to change. Support the End Of Life Choice Bill. Do not get confused between euthanasia and suicide.

They are very different things.

Any person with a terminal disease should have the basic human right to say enough is enough my life is complete, on their own terms.

*Brendon Rope is the son of Don Rope, deceased by MND 1 January 2016. Views expressed here are the writer's and not those of Hawke's Bay Today.*

[Rev John Fox Responds to Brendon Rope](#)

Rev John Fox | NZ Herald | 31 January 2018

I read Brendan Rope's story of his father's battle with motor neurone disease with sadness.

Stories of such weight are half the argument for assisted dying, and we should take them seriously.

But we should also take seriously the assumptions about disability the article also displays. As a trustee of a disability charity, I know many people who can't speak. Many people who can't feed themselves.

As a sufferer of spastic hemiplegia, I too am in daily pain. I too am frustrated, and angry, and crying, and sad. Our elderly in rest homes, dementia units, and hospitals too know the frustrations of not being able to care for themselves: the pain of having to depend on others.

But when you argue that you'd rather be shot than live a disabled life, your argument has profound implications for the value of disabled people, and for those who also have motor neurone disease, spina bifida, or like me, cerebral palsy.

We have two options here: view dependency as a degrading and horrible crime (which puts human beings who are dependent on the same level as a sick sheep), or we can do what we do with all other forms of suicidality: youth suicide or elder suicide, and come around the person with proper medical treatments, family and community solidarity, and meaning.

Mr Rope announces that suicide is a very different thing to euthanasia, but offers no arguments why this is so—from the disabled corner, I argue it's exactly the same.

### [New Zealand Medical Association: Position Statement Euthanasia \(Approved 2005\)](#)

The NZMA is opposed to both the concept and practice of euthanasia and doctor assisted suicide.

Euthanasia, that is the act of deliberately ending the life of a patient, even at the patient's request or at the request of close relatives, is unethical.<sup>40</sup>

Doctor-assisted suicide, like euthanasia, is unethical.<sup>41</sup>

The NZMA however encourages the concept of death with dignity and comfort, and strongly supports the right of patients to decline treatment, or to request pain relief, and supports the right of access to appropriate palliative care.

In supporting patients' right to request pain relief, the NZMA accepts that the proper provision of such relief, even when it may hasten the death of the patient, is not unethical.

This NZMA position is not dependent on euthanasia and doctor-assisted suicide remaining unlawful. Even if they were to become legal, or decriminalised, the NZMA would continue to regard them as unethical.

(Note: this policy replaces the earlier Euthanasia policy of 1996, which was reconfirmed in 2001.)

### [Leave Doctor's Out of it: www.docstorssayno.nz](http://www.docstorssayno.nz)

Euthanasia and assisted suicide (EAS) are not medical treatment, are not compatible with medical ethics, and undermine good medical practice.

- In the 2015 Report on Assisted Suicide (Scotland) Bill, both supporters and opponents of the Assisted Suicide Bill acknowledged that “the involvement of healthcare professionals in assisted suicide, even if it were legal, would not amount to ‘medical treatment’”.<sup>42</sup>
- Medical associations, within New Zealand and internationally, hold that a doctor's duty of care does not include deliberately ending a patient's life.
- The World Medical Association and the New Zealand Medical Association both state that EAS would remain unethical even if it was legalised. Other key NZ professional medical groups, including the Australia & New Zealand Society of Palliative Medicine, Australian and New Zealand Society for Geriatric Medicine, Hospice New Zealand, and Palliative Care Nurses New Zealand, are also opposed.

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<sup>40</sup> World Medical Association Declaration on Euthanasia, October 1987.

<sup>41</sup> World Medical Association Statement on Physician Assisted Suicide, September 1992.

<sup>42</sup> Health and Sport Committee, “Stage 1 Report on Assisted Suicide (Scotland) Bill,” (2015), n. 207, [www.parliament.scot/S4\\_HealthandSportCommittee/Reports/her15-06w-rev.pdf](http://www.parliament.scot/S4_HealthandSportCommittee/Reports/her15-06w-rev.pdf).

- It is argued that doctors who do not wish to participate will be able to exercise conscientious objection. However, overseas experience shows doctors and health institutions become subject to various forms of coercion, raising serious doubts as to whether, in the long-term, they would be adequately protected by conscientious objection, even when this is enshrined in law.
- A physician “processing a request for euthanasia, is working in the opposite direction to a physician who is working to improve the quality of the patient’s life ... the underlying assumption in processing a request for euthanasia is that this is a life that’s no longer worth living, whereas the premise underlying a desire to improve quality of life is that the patient has a life worth living.”<sup>43</sup> If the doctor explores and processes a request for EAS, the doctor affirms the patient’s outlook that their life is not worth living.
- Euthanasia regimes are predicated on the subjective notion that some lives are no longer worth living. Conversely, ethical medical practice is predicated on the idea that doctors eschew their subjective judgements about persons they are treating, which is why, for example, doctors do not refuse to treat the ‘enemy’ in times of war. Thus, EAS introduces an inherent and unacceptable contradiction into medical care.
- It is readily accepted that ‘coercion’ presents the most significant risk for an EAS regime. “Detecting coercion is extremely difficult. Doctors are not in a position to do this.”<sup>3</sup> There are others, such as lawyers or psychologists who, because of their training and experience, are in a better position to detect coercion and assess capacity.
- The most common argument “that patients have a right to control when and how they die – in fact points to the involvement not of doctors but of legal agencies as decision makers, plus technicians as agents.”<sup>44</sup>
- Doctors are not necessary for the regulation or practice of EAS. “Even if our wider society were to make this practice lawful it would remain essential that the Medical Profession stand apart from any participation in it.”<sup>45</sup>
- “... the majority [of doctors], for moral, ethical, legal and professional reasons, do not wish to become involved in killing their patients ... Doctors are not a necessary step in the process they are a very convenient tool for legislators to abrogate their responsibility and pass it to a caring profession.”<sup>46</sup>

Euthanasia and assisted suicide (EAS) place our elders at risk of a premature death.

- Our society, with its overt emphasis on individuality, independence and productivity, has taken on a strongly ‘functionalist’ flavour – dignity is identified with being strong, self-reliant, fit, healthy and useful. This mind-set has fostered an increasingly ‘ableist’ and ‘ageist’ culture in which it is a weakness to become a ‘burden’ to others. *This context puts our elders at risk of EAS coercion as a result of social prejudices.*

<sup>43</sup> Affidavit of Baroness Ilora Finlay on Behalf of the Defendant, (2015), n. 99, p. 26, [http://carealliance.org.nz/wpcontent/uploads/2015/11/crown\\_finlay.pdf](http://carealliance.org.nz/wpcontent/uploads/2015/11/crown_finlay.pdf).

<sup>44</sup> F. Randall, and R. Dowie, “Assisted suicide and voluntary euthanasia: role contradictions for physicians,” *Clinical Medicine* 10.4, (2010), p. 323.

<sup>45</sup> New Zealand Health Professionals Alliance, “Viewpoint: Why the Royal New Zealand College of General Practitioners needs to have a Position Statement on Euthanasia,” (2017), <http://www.nzhpa.org/general-practitioners-professionalsroyal-new-zealand-college-general-practitioners-needs-position-statement-euthanasia/>.

<sup>46</sup> Dr Ron Jones, “Leave doctors out of ‘assisted dying’ discussion,” *The New Zealand Herald*, (2017), [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11823577](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11823577).



- Those of our elders who are subject to a loss of physical and mental function, and consequently a loss of autonomy, become exceptionally vulnerable to internalising the (negative) messages from a functionalist societal narrative that advantages and promotes the strong and independent. *This context puts our elders at risk of EAS coercion as a result of their own internalised feelings of loss of worth.*
- The number of older persons requiring support is rising as the ‘baby boomers’ generation reach retirement age. In a context in which there are growing pressures on our health system,<sup>47</sup> growing pressures on providing sufficient places and carers for our elders,<sup>48</sup> and growing economic pressures on families, families and the State find themselves less able to provide care at the very time the needs are greatest. *This context puts our elders at risk of EAS as a result of EAS coercion from families and caregivers.*
- The levels of elder abuse in New Zealand continue to rise *in spite of tough laws and policies.*
- Age Concern reports that it receives more than 1500 confirmed referrals for older people facing elder abuse or neglect each year. It has been estimated that only 16% of actual elder abuse cases come to the attention of service agencies such as Age Concern, which makes the total number around 9,300. Age Concern reports that 75 percent of cases seen involve psychological abuse. 75 percent of alleged abusers are family members.<sup>49</sup>
- While Seymour’s bill purportedly provides protection against abuse or coercion by requiring verification from a medical practitioner that the person making the request is free from coercion,<sup>50</sup> “there is no way to guarantee the absence of coercion in the context of assisted suicide” or euthanasia.<sup>51</sup> The different forms of coercion are not only hard to detect, but doctors are not trained to detect such coercion.
- A wish to die prematurely is recognised by professionals as arising from underlying depression, financial concerns or family dynamics.<sup>52</sup>
- Evidence from Oregon indicates that the most common end of life concerns are not about pain control but relate to existential questions; ‘being less able to engage in enjoyable activities’, ‘loss of autonomy’, ‘loss of dignity’, and ‘being a burden on family and friends’.<sup>53</sup>
- There is a growing sense of social isolation amongst our elders in New Zealand. In the New Zealand Longitudinal Study of Aging, 41.2 percent of participants were categorised as ‘moderately lonely’, 7 percent as ‘severely lonely’ and 3 percent as ‘very severely lonely’. Less than half (48.8 percent) of the participants were categorised as ‘not

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<sup>47</sup> Lyndon Keene, Philip Bagshaw, et al. “Funding New Zealand’s public healthcare system: time for an honest appraisal and public debate,” *The New Zealand Medical Journal* 129, 1435 (2016), <https://www.nzma.org.nz/journal/read-thejournal/all-issues/2010-2019/2016/vol-129-no-1435-27-may-2016/6891>.

<sup>48</sup> Helen King, “Aged-care sector warns of workforce crisis”, *Stuff*, (2017), <https://www.stuff.co.nz/business/99454652/agedcare-worker-fears-for-future>.

<sup>49</sup> Age Concern, “Elder Abuse and Neglect,” [https://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ Public/Elder Abuse and Neglect.aspx](https://www.ageconcern.org.nz/ACNZPublic/Services/EANP/ACNZ%20Public/Elder%20Abuse%20and%20Neglect.aspx)

<sup>50</sup> New Zealand Health Select Committee, “Ending One’s Life in New Zealand,” (2017), p.2, [https://www.parliament.nz/resource/en-NZ/SCR\\_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24](https://www.parliament.nz/resource/en-NZ/SCR_74759/4d68a2f2e98ef91d75c1a179fe6dd1ec1b66cd24).

<sup>51</sup> Health and Sport Committee, “Stage 1 Report on Assisted Suicide (Scotland) Bill,” (2015), n. 194, [www.parliament.scot/S4\\_HealthandSportCommittee/Reports/her15-06w-rev.pdf](http://www.parliament.scot/S4_HealthandSportCommittee/Reports/her15-06w-rev.pdf).

<sup>52</sup> Australia & New Zealand Society for Geriatric Medicine, “Points for reference with regard to ANZGSM and Euthanasia,” <http://www.anzsgm.org/documents/PointsforreferencewithregardtoANZSGMandEuthanasia11817.pdf>.

<sup>53</sup> Oregon Public Health Division. Oregon Death With Dignity Act: Annual Reports, <http://www.oregon.gov/OHA/PH/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/pages/index.aspx>.

lonely'.<sup>54</sup> Loneliness is related to poorer health outcomes, depression and the loss of a will to live.

- There is also evidence that certain groups of older persons suffer high rates of depression. The New Zealand LiLACS longitudinal study found the prevalence of depression ranged from 15 percent for Māori men and women and from 10-12 percent for non-Māori men and women.<sup>55</sup>
- When the symptom driving requests for assisted suicide is psychological distress “the standard of care for depression and demoralization is not a lethal dose of barbiturates.”<sup>56</sup>

**Conclusion:** There has never been a more dangerous time, as far as our elders are concerned, to contemplate legalising euthanasia or assisted suicide. Our elders will find themselves having to increasingly justify their right to life, and the so-called ‘right to die’ will be increasingly perceived as a ‘duty to die’. *This is not real choice*. EAS will place many of our elders at risk of a premature death under the *guise* of ‘personal choice’. This is unacceptable, particularly because it is well known that persistent requests for euthanasia are extremely rare when patients have access to quality palliative care.

## The Royal Australian and New Zealand College of Psychiatrists

Mental illness is no basis for euthanasia<sup>57</sup>

22 September 2016

Euthanasia and physician assisted suicide continue to be widely debated in our community, and the Royal Australian and New Zealand College of Psychiatrists (RANZCP) is committed to contributing to discussions around this complex and emotive issue.

‘The RANZCP does not believe that psychiatric illness should ever be the basis for physician assisted suicide,’ said RANZCP President Professor Malcolm Hopwood.

‘Unrelievable psychiatric suffering is rare, and ensuring that a person suffering from mental illness has the appropriate capacity to make decisions in this context poses significant challenges. Mental illnesses are treatable, and there are many ways to get help.’

The RANZCP is also concerned about the potential impact of the debate about euthanasia on older persons.

‘There is a misconception that suicide in older people is largely driven by suffering associated with chronic, debilitating or terminal illness, whereas the factors behind suicide amongst older people

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<sup>54</sup> Jack Noone and Christine Stephens, “The New Zealand Longitudinal Study of Ageing: Summary Report – Social Integration, Health and Quality of Life,” *Massey University*, (2014), [http://www.massey.ac.nz/massey/learning/departments/school-of-psychology/research/hart/publications/projectreports\\_nzlsa.cfm](http://www.massey.ac.nz/massey/learning/departments/school-of-psychology/research/hart/publications/projectreports_nzlsa.cfm)

<sup>55</sup> Teh, R., Kerse, N., Kepa, M., Doughty, R. N., Moyes, S., Wiles, J., ... & Mace, C. (2014). Self-rated health, health-related behaviours and medical conditions of Maori and non-Maori in advanced age: LiLACS NZ. *The New Zealand Medical Journal (Online)*, 127(1397).

<sup>56</sup> HR. Greene, “Letter to the council on ethical affairs,” *California Medical Association*, (2006), Available at [http://dredf.org/assisted\\_suicide/greene.shtml](http://dredf.org/assisted_suicide/greene.shtml).

<sup>57</sup> <https://www.ranzcp.org/news-policy/news-archive/news-archive-2016/mental-illness-is-no-basis-for-euthanasia>

are complex', said Professor Hopwood. 'The RANZCP calls for open debate on developing an integrated approach to service provision for the elderly focusing on their well-being, maintaining their independence and improving their quality of life.'

The RANZCP considers that the primary role of medical practitioners – including psychiatrists – in end of life care is to facilitate the provision of good quality, comprehensive and accessible patient-centred care. Palliative care should strive to achieve the best quality of life during the final stages of patients' illnesses and allow patients to die with dignity. This should be adequately resourced and widely available.

Currently, physician assisted suicide is illegal in all Australian jurisdictions and in New Zealand however surveys in both countries indicate reasonable support for the legalisation of some kind of medically assisted dying. The RANZCP has developed a [Position Statement](#) to contribute to public discussions, and has made a recent [submission](#) to the New Zealand Health Select Committee's investigation into ending one's life in New Zealand.

For more information on the RANZCP's views on physician assisted suicide see:

- [Position Statement 67: Physician Assisted Suicide](#)
- [Submission to the Health Select Committee's investigation into ending one's life in New Zealand](#)
- [Submission to the Senate Legal and Constitutional Affairs Legislation Committee Inquiry into the exposure draft of the Medical Services \(Dying with Dignity\) Bill 2014](#)

### [Dr Lara Hoskins: Submission to Select Committee](#)

I oppose the legalisation of euthanasia and assisted suicide. Our current laws protect the vulnerable and changing them would put many at risk of unwanted, premature death. I believe that the imperative to protect the vulnerable is a key issue in this matter.

I work as a palliative medicine physician across both hospital and community settings. I began working in palliative care in 2005. In my training and my current practice I have had many patients request euthanasia. These requests give me an opportunity to explore the reasons they ask for it. This aids me in helping address what is most troubling to them. In the vast majority of cases the underlying concern which prompted the request can be addressed and the desire for euthanasia goes.

In my experience the vast majority of patients who persistently ask for assistance in hastening death are those who have defined their sense of value and worth by their functional capacity. Thus when illness or injury threatens their function they seek to hasten their death. Their symptoms, including pain, are often only mild or moderate but the loss of ability is the aspect they find unbearable. A very small number of patients desire euthanasia due to severe, unremitting pain.

If we remove the current protection and assist people in killing themselves or others when they feel their impairment is unbearable it would send a message to others with disability that their lives are not as valuable as able bodied people. This is likely not to be overt but the message will be heard.

For many of my patients their first priority is not to be a burden. This often outranks personal comfort. Being a burden is not an objective, measurable quantity. It is the perception of the individual. Family and friends willingly care for a person and do not feel burdened but the patient feels the strain their illness causes is too great. The best answer to this issue is not to help the patient kill themselves. It is to support the person and their caregivers. Death is irreversible. People frequently change their mind in a desire for hastened death.

I have known many patients who would have taken the option to kill themselves in order to ease the perceived burden on others. Some may say that this is their right to choose. It would not have been a free choice it would have been coercion. Their preference would be to live and enjoy as

many days as they could but they feel compelled to do otherwise. Currently the law protects them and this is a good thing.

Our current medical therapy is not perfect and people with terminal illness do suffer. For the most part symptoms can be controlled. For some the pain medications are ineffective and sedative medication can be and are used to ease their suffering. The suffering of a few should not lead us to remove the protection from the majority and put them at risk of inappropriate, early death.

I believe that the option to decline medical intervention is right and that refusing life prolonging treatment is a reasonable option for patients. Deliberately killing a person or assisting them in killing themselves is wrong and a completely different matter. If it were to be legalised in New Zealand then I believe that doctors should play no role in it. It is at odds with what we stand for and our ethical principles.

I am concerned by the data and reports from medical practitioners working in places where assisted suicide or euthanasia is legal. I believe that it shows there is a slippery slope with a widening of the population to whom the option of early death is available. There is evidence of an increasing number of people killed involuntarily. This is alarming and should be a warning to us.

I support the Australia New Zealand Society of Palliative Medicine (ANZSPM) position statement on Euthanasia and Assisted Suicide.

Every person is valuable and matters. They matter regardless of age, race, mental capacity or function. I recommend that assisting suicide and euthanasia remain illegal.

[Elevate Christian Disability Trust: Submission on the End of Life Choice Bill](#)

## **1. About Us**

Elevate Christian Disability Trust has been supporting people with disabilities for over 30 years. We have been empowering people with disabilities to live to their full potential –physically, mentally, socially and spiritually. We do this through our branches, our ministries to disabled people, (Christian Fellowship For the Disabled) the blind, (Torch) and the intellectually disabled, (Joy Ministries) our drop-in centre in Auckland, our family ministries, and our camps.

## **2. Position on the Bill**

We oppose any change to the current law that would enable assisted suicide. We therefore oppose this Bill in its entirety.

We ask to be heard in person.

## **3. Supporting Reasons**

As a charity which supports the disabled, we oppose any law change which will undermine our hard-won position in New Zealand society. We believe assisted suicide has the potential to do this, by converting the disabled into a killable category of people no longer protected by the ordinary law.

## 1. Assisted Suicide and fear of disability go hand-in-hand.

We note that fear of disability, and marginalisation of disabled people, are still social problems, ones we deal with every day. We argue that any choice to die (whether by suicide, or by requesting assisted suicide) inevitably reflects, and to a large extent, is shaped by, attitudes about disability. The reports from Oregon highlight such attitudes.<sup>58</sup> The things people fear, such as loss of autonomy, inability to participate in parts of life, being a burden, or being out of control of one's body, are every day realities for disabled people. The idea that an incurable or terminal condition undermines one's dignity is not one we accept, since so many Elevate members continue to live full and flourishing lives, despite their conditions. The idea that being out of control of one's own body and destiny should discount the value of one's own life is likewise an idea shaped by fear, and prejudice. We know that disability brings frustrations and cruelties with it. But we also submit that, in the vast majority of cases, disabled people, even terminal and incurable ones, can live meaningful lives, shaped by solidarity, kindness and gift. It is that meaning, and that solidarity, assisted suicide attacks, replacing the hard, but extremely valuable sharing of pain, kindness and responsibility with the instant option of a quick death. This idea, once accepted, undermines the position of all disabled people. The notion that one is "better dead than disabled" is not one we accept: we find it insulting and discriminatory.

Section 4 of the Bill extends suicide to those with a "grievous and irremediable medical condition" and an "advanced state of decline in capability" who experiences "unbearable suffering in a manner he or she considers tolerable". This section is broad, vague, subjective and dangerous. It is stuck to no objective criteria, and institutionalises the idea that a suicide from someone in such a condition (that is, someone with a painful incurable condition) is not only excusable and condoned, but State supported to the extent of forcing doctors to co-operate in it. This attitude to suicide not only undermines suicide prevention, but opens the suicide option to a huge demographic of vulnerable people based on a subjective notion of grievous suffering. Whether the author of the Bill intends this or not, this is what the words say: and people even with mild disabilities which are permanent and painful (like cerebral palsy, arthritis, mental illness or paraplegia, as well as illnesses attendant on old age) are potentially eligible. This clause undermines the value of disabled life, attacks the progress disabled people have made in being able to have our suicide treated in the same way as able bodied people, and undermines long term the social position of disabled

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The three top reasons for assisted suicide are cited as "loss of autonomy (93.0%), decreasing ability to participate in activities that made life enjoyable (88.7%), and loss of dignity (73.2%)."  
Oregon Public Health Division, *2013 DWDA Report*, 6 (see following page for link)  
<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf>

people. We agree with the Human Rights Commission, who reminded the country in their submission to the Health Committee that:

“Community attitudes to people with a disability and concepts such as “quality of life” affect the way that disability is perceived and the way in which disabled people value themselves and form their own identity.” Fear of becoming disabled, or of becoming a “burden”, on family members and others can have an impact on the decisions that disabled people might make around end of life choices.”

“Such views may not be based on lived experience or personal knowledge of a particular disability but on information or attitudes shaped by the broader community. These can also be influenced by actual or perceived difficulty accessing appropriate services and support that would allow disabled people to participate equally in the community on the same basis as others. It is likely that these societal influences and attitudes, at least in part, may shape the views of some members of the broader community as to decisions they might make in future if they were incapacitated or became ill.” (Human Rights Commission Submission 40-1)

We therefore urge the Committee to consider what message assisted dying sends, not simply to the tragic hard cases who have asked for it, but to the many disabled people who ask, every single day, what their lives and contributions are worth to the society they live in. We submit that this is not primarily a question of individual choices in this or that hard case, but about the value of disabled life in the longer term.

The value this Bill puts on disabled life, by contrast, is easily determined: the penalty for an avowed wrongful death is \$10,000 or three months in prison. Compare this with penalties for able bodied murder or manslaughter and you will see exactly how discriminatory this Bill is. That is the culture we live in, and the Bill now wishes to add Nembutal to as a treatment option on the back of it: a not so subtle message to disabled people that our lives are worth less. In such a culture, choices are not equal, and the impact of this law will not be equal either.

We flatly reject the assumption that disability takes away from dignity. Many Elevate clients have incurable and painful conditions. But we have dignity. Simply by being human beings, we submit, we are part of the family, and entitled to the protection of the ordinary law in exactly the same way as anyone else. Pain, isolation, the presence of decay and limitations on bodily autonomy are every day realities for many Elevate clients. They do not make us undignified, or take away from our value. They may mean we have obstacles to face, and adaptations to make. They do not mean that our human rights are up for debate, or that our lives are valueless.

We urge the Committee to consider the message this debate is already sending to disabled people about their value to the rest of us. A choice to commit suicide when your life is

disabled like ours impacts us. It also makes a difference to society, and to all human beings, when one of us opts out.

## **2. Assisted Suicide undermines medical trust**

Assisted suicide, as opposed to ordinary suicide, takes the cooperation of medical professionals. This undermines the trust which is an essential ingredient of the patient-doctor relationship, and does it for everyone. The whole basis of the medical relationship is predicated on the principle that the doctor is there to cure, not kill. Not only has assisted suicide huge implications for medical conscience, and for doctors in general, but also for patients, especially disabled and vulnerable ones, who trust their doctors. We oppose any measure, like assisted suicide, which makes the disabled and the elderly more vulnerable. We also note that sometimes doctors get it wrong—and to give them the power of life and death in a new way is not only burdensome to the doctor, it is also dangerous for the patient. We stand with the NZMA and the other medical organisations who are maintaining their professional ethics which are predicated on “first, do no harm”. We submit this foundational principle is key to allowing the safe vulnerability of the severely disabled we serve. We also oppose any attack on medical conscience, including the duty of compulsory referral for suicide, which section 7 contemplates. We also consider that the rigid repetition of “must” in sections 11-15 of the Bill disempowers doctors to use their professional judgement; suicide is seen by the current draft of the Bill as the default option which the doctor must offer if the patient requests it; we submit this is outrageous: this legal production line marching inevitably towards one outcome does not describe properly or appropriately the large emotional toll severe illness takes upon our clients, in which conflicting emotions, severe mood swings, and prolonged depression are common, over a period of years, before new vitality and meaning manifest themselves. We are committed to the long and difficult work of rehabilitation, support and encouragement: it is exactly this work which suicide precludes and cuts short, with little thought, less care, and no prudence at all. We consider the utter horror of Section 27, in which proper investigations are actively forbidden, representative of the Bill's shoddy drafting, and cavalier disregard of the safety of disabled, terminally ill, and vulnerable people.

## **3. Safeguards inadequate**

The safeguards upon which we hear so much are likewise deeply flawed and inadequate. We are astounded that ending someone's life is not only contemplated by the Bill, but is potentially allowed, when the person is found to be competent with no specialist or psychiatric analysis, a time limit, and in a manner which simply assumes that someone can properly judge not only the value of their own lives (something we do not assume with youth or elder suicide), but the likely prognosis and future outcomes, supported only by two GP s who by their presence on the Registrars List already have an ideological preconception

in favour of suicide, and potentially no other advice or support. We find this not only outrageous and unrealistic, but dangerous. We also find it contrary to the lived experience of the disabled people we serve. People with incurable conditions often experience depression and a sensation of meaninglessness; Statistics NZ pointed out in 2015 that pain is a risk factor for suicide. We are familiar with these problems. But we submit that the proper solution to them is wrap-around support, strong relational bonds, and proper palliative care options. In the rare hard case where these fail, this is not primarily a legal, but a medical question, and we submit the Bill, by creating a category which is so broad, vague and badly drafted, is unlikely to address the root causes of even these hard cases.

We oppose creating a category of people whose lives can be shortened based on illness. We also submit that this is not a question of fixing a few loopholes, or polishing a rough diamond. The State should not kill people. Doctors should not kill people. The only way to make *sure* that that does not happen is to reject the entire principle, and therefore the entire Bill.

#### **4. Assisted Suicide is inconsistent, and discriminatory**

If an able-bodied person asks to die, the doctor immediately asks questions about the status of the person's support or connectedness, the reasons they wish to die, medications, and life, in an effort to offer proper support. If a disabled, terminal or incurable person asks to die, then the Bill wishes the request to be able to be granted. The salient difference is the able-bodiedness of the individual. We submit this is discriminatory. We stand with DPA, Not Dead Yet Aotearoa, the Disability and Faith Network and other medical and disability sector professionals in rejecting this principle.

#### **5. Suicide is not medical care**

We submit that in a time of fiscal austerity, and with an aging population, with a high suicide rate, and discrimination against disabled people continuing a problem, we ought not to offer killing (even at one's own request) as an acceptable medical alternative. Pressure upon elderly people to get out of the way, more expensive palliative care being elided in favour of death, and disabled people's safety at risk; all of these things become more likely if this Bill goes any further.

#### **6. Conclusion**

Elevate CDT stands for inclusion of disabled people in society, the real dignity of the disabled, and for the good neighbourliness which is the foundation of any decent society. We oppose assisted suicide because it colludes with anti-disabled discrimination, and creates a category of people who can be killed because of their disability. We oppose assisted suicide because choices are not made in a vacuum, and there are too many



appalling risks associated with allowing suicide. And we oppose assisted suicide because it undermines the solidarity and good neighbourliness upon which our society depends. In the name of a fake compassion, assisted suicide substitutes killing for curing, and denies both disabled and able-bodied people the full contribution both can make to the lives of the other. We submit that this Bill should not proceed.

### Voluntary Assisted Dying (VAD) in New Zealand: Jack & Glynis Havill Submission

- Jack Havill is a retired Intensive Care Medicine Specialist. He was Dean of the Joint Faculty of Intensive Care NZ and Australia and Head of the Waikato Clinical School (Auckland University). He was awarded an ONZM in 2005 for services to research and intensive care medicine. He is also a past President of the Voluntary Euthanasia Society NZ (now called the End-of-Life Choice Society).
- Glynis Havill is a retired Registered Nurse who has nursed many terminal patients in both private hospitals and at their homes. She is a member of the NZ Nurses Organisation and on the Midland NZNO Council.
- Both have been active members of the Christian Church throughout their lives.

### Summary

1. We believe that the present Bill is sound and provides adequate safeguards for a requesting person who is competent. We would be very concerned if there was watering down of the Bill, or that increased blocks for the patient are incorporated e.g. court involvement, for the two categories of illness described in the Bill.
2. However, we believe that there should be an addition to the Bill that will also allow a person to write an Advanced Directive while competent. This will allow Voluntary Assisted Dying (VAD) later should the patient become incompetent, but still fulfil the illness and suffering criteria e.g. severe dementia. The issues around use of an End of Life Advance Directive in this situation are discussed on pages 31-35 in this submission. When a person has become incompetent, VAD may necessitate extra safeguards e.g. compulsory involvement of family and the Family Court.
3. Opponents of VAD are very vocal and this often comes from the Catholic Church and other religious groups. This paper attempts to address the oft repeated concerns of this group, including some specifically Christian issues. Both submitters have a strong Christian belief and feel that we can contribute to the debate in this area.
4. Statements opposing VAD were constantly made by individuals and groups to the Health Select Committee Enquiry (2015-2016) include:
  - Sanctity of life is important and would not be respected with VAD
  - Withdrawing of life support is presently allowed because it is 'different' ethically
  - VAD means 'killing' and is equivalent to 'murdering' a patient.
  - Autonomy of the patient should not be allowed as in VAD, because it will lead to harm in society
  - Slippery slope – meaning shifting ethical norms with VAD will be a danger to society.
  - Vulnerable people, especially the elderly or disabled will be coerced/abused, especially by family should VAD be legalised.
  - Palliative Care/Hospice is totally adequate to relieve suffering, and the 'double effect' is totally different from VAD because 'intent' to cause death is avoided. 3

- Relationship between the doctor and patient under VAD will be destroyed because the doctor is there to heal, not kill
- Suicide is the same as VAD and suicide will be encouraged if VAD is allowed
- Spiritual counselling and precious time with family will be destroyed with VAD • Sacrifice is very beneficial to the patient and those caring for them
- Christians should not have anything to do with such a law. 'It is against my religion' was a common submission.
- Doctors and nurses do not support passing a law allowing VAD

The assertions in (4) above are not supported by good evidence. If the Select Committee is unwilling to believe the investigations of other countries such as Canada and Victoria (Australia) which looked at these assertions very carefully, then they should visit and consult with legalised jurisdictions such as the Netherlands, Belgium, Oregon and Canada, who now have significant histories with VAD. Careful note should be taken of the extensive considerations of Canadian enquiries, including the statements of the Canadian Supreme Court, which discussed all of the above issues and found that none of the above statements in (4) above were sustainable.

Most of our subsequent discussion addresses these issues.

(The complete text of the 35-page submission is available here:

[https://www.parliament.nz/resource/en-NZ/52SCJU\\_EVI\\_74307\\_19775/19257d22ea508d6dd059cc1a25d5fbe88bb98078](https://www.parliament.nz/resource/en-NZ/52SCJU_EVI_74307_19775/19257d22ea508d6dd059cc1a25d5fbe88bb98078))

# Part Four: International Voice

## Netherlands Rob Jonquière MD: Submission to Justice Select Committee

Rob Jonquière MD  
WF Executive Director

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NL 1019 HK AMSTERDAM  
The Netherlands

Amsterdam, Friday, April 5, 2019

I consider myself as having extensive experience in the field of legalization of medically assisted dying.

As Family Doctor (1972-1985) working in general practice I took the position that end-of-life talks with my patients were an essential part of the doctor-patient relationship and could (and actually did) lead to decisions to on an explicit request actively end the suffering by terminating the life.

As Head of GP Vocational training (1985 – 1995) I made it a point that the issue of dying guidance in its broadest sense (so including issues as palliative care and medically assisted dying) had to be an important part of the training scheme.

As CEO of the Dutch Right to Die Society NVVE (1999 – 2008) I have been involved in the public and parliamentary discussions around the implementation of the Dutch Euthanasia Bill, right from the moment it was introduced in the Dutch Parliament in 1999, up to its endorsement by the Senate in 2001 and its implementation in 2002 and later evaluations.

In my current position as WFRtDS Executive Director (2008 – to date) I have been able to explain to great extents the ins and outs of the Dutch law in many countries in the world.

I visited New Zealand in 2015, touring the country, presenting the Dutch case and its possibilities for NZ in a large number of well visited public meetings, to both organizational and political officials and health care professionals.

My thus built experiences have learnt me to understand on one side the impossibility to export Dutch Law to other countries one-in-one (how much national Right to Die Societies would sometimes like to) because of differences in cultural and juridical/legal systems, but also on the other side they have taught me that “our” experience (now some 35 years of tolerated and legalized practice) forms a sound basis and even may provide valuable concrete contributions for other jurisdictions to design their own law; to design a system in which – this turned out in The Netherlands to offer the most important effect – the quality of end of life care could be improved, also because the patient with this legal possibility got a real choice at the end of his/her life, to terminate unbearable, futile suffering.

I am glad to have the opportunity to present to you my comments and views on the issues and questions raised by this End of Life Choice Bill.

This submission is in writing, but I will be happy to – in whatever communication-form you deem appropriate – also be heard by the Select Committee for an oral submission because in such a situation I will be better able to address the issues that you want to be clarified and provide more specific answers to the specific questions you may have.

For clarity I offer you here to begin with the definitions for the words and concepts on end-of-life-decisions I use:

Euthanasia: deliberate termination of life by someone else, on the explicit request of the person involved, by injecting the medication. In the Netherlands, Belgium and Luxembourg only doctors, who must comply with the criteria of the law, will not be prosecuted after reporting their case. One of those criteria, and possibly the most essential next to the request, says there should be a situation of unbearable and hopeless suffering.

**NB!** Thus terminal/palliative sedation, non-treatment decisions or involuntary termination of life, all are NOT euthanasia.

Medically Assisted Suicide: prescribing (and providing) the medication to be taken orally by the patient by the doctor and on request. Medically is sometimes (as in specific titles of Laws) substituted with Physician – causing no difference in interpretation.

Medically Assisted Dying: is used for both (separate or in combination) ways of doctors assisting patients in their dying process: injection or prescriptions, and is nowadays a more generally used term, also to avoid misunderstandings caused by using different definitions.

I will – when speaking in general terms – use in my submission the term *Medically Assisted Dying*, without implying preferences for either of the possibilities. When using Euthanasia or Suicide, I then refer to specific Dutch national situations or laws.

### *1. The factors that contribute to the desire to end one's life.*

The developments in health care and medicine have seen to the current situation in which patients could be better treated and live longer. Where in the past mainly infectious diseases – then untreatable – contributed to the dying of patients, this way of passing away was fierce, but short and leading to an inevitable death. Nowadays, because we can treat infectious diseases, the diseases leading to death are as fierce, but take longer, cause more suffering. The treatments developed now are not always 100% successful but result in prolonging lives, but because of that also sometimes in prolonging a period that can be pestered with unbearable suffering.

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*It is important to make a clear distinction between “ending a life” and “terminating (unbearable) suffering”. I have never seen or heard terminal patients say they wanted to die; they did not want to continue this sort of life because of untreatable suffering. Medically Assisted Dying relates to suffering and not ending lives.*

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Certainly when the (unbearable) suffering cannot be treated well, when even the best palliative care is not able to do make life comfortable, or when the prospect is hopeless, the meaning of life may

dwindle so much, that some patients want to put an end to that suffering by having their life terminated, rather than going on leading a life with such a bad quality.

### *2. The effectiveness of services and support available to those who desire to end their own lives*

Except for those countries and jurisdictions where (medically) assisted dying is legal, those who desire to end their own lives have only one choice: suicide. In most countries around the world that is not illegal, but assistance is. And what constitutes “assistance” is many times at the base of disturbing interpretational discussions.

Desiring to end one's own life, implies one desires to die in a humane way: not by horrifying actions (trains, flats, shooting) but quietly and without leaving the people around you with a mess. The means for such a choice are scarce and only available through trick and deceit (feign complaints to get prescriptions from your doctor) or through internet (where one should doubt the reliability of the goods received).

It all – in the end even when bystanders illegally do give humane assistance- leads mostly to secrecy and possible danger for failures with sometimes disastrous consequences

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*Having no real choice at the end of someone's life for assistance with dying, will either lead to unnecessary prolonged suffering and dying, or to the use of inhumane steps for suicide or illegal assistance.*

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### 3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation.

In my 2015 tour through New Zealand (on invitation from End-of-Life Choice VES NZ) I have met large audiences expressing their wish for a change in the law. They conveyed to me the same message as the polls on this issue in New Zealand from the last couple of years did: a vast majority of New Zealanders are in favor of such a change by which they could make real choices at the end of their life, when suffering became unbearable without any hope for improvement. The current NZ laws do not give that sort of choices.

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*As everywhere in the world, also the New Zealander is in majority in favour of legalisation of (medically) assisted dying.*

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### 4. International experiences.

In addition to already longer existing possibilities (Switzerland, Belgium, Netherlands, Luxembourg, Oregon USA, Colombia, Canada and Victoria in Australia) I see a gradual development into more and more legalization activities worldwide; activities that are supported all around the world with always vast majorities of the population (> 70%):

- a number of Australian States (New South Wales, Northern Territory, South-Australia), encouraged by the Victoria success have ongoing parliamentary debates on medically assisted dying, in which a positive result is getting nearer and nearer;
- Colombia has finally turned a longstanding Supreme Court of Colombia verdict (the basis for a case law situation allowing medically assisted dying in that country) into a formal Euthanasia Law;
- More USA States now – following Oregon – have legalized physician (medically) assisted suicide (Vermont, Washington, California, Montana) and many other States are on their way to do the same;
- South Africa recently started their debate with a positive decision from their Supreme Court (2015);

- More countries in Europe (France, UK, Ireland, Sweden, Spain, Italy) are on their way to debates in their respective public and Parliamentary bodies.

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*International information to be found on [www.worldrtd.net](http://www.worldrtd.net)*

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### *BROADER and GENERAL COMMENTS.*

To my relief I notice that in the Explanatory note, lessons from former hearings and experiences have been used to elaborate on important details, and in my view ameliorate the whole draft.

In the following I will use the Dutch experiences with the development, discussions and implementation of a law, from which I hope to be able to contribute to the development of a NZ Assisted Dying Law that makes use of such valuable foreign experiences and advises, a law that fits in properly with the NZ culture, with the NZ health and juridical system and one from which people may benefit if eligible and be protected if not-willing to die (yet or in such a way).

### Supportive factors

It is clear that next to the Dutch *culture of “toleration”* leading to early (first one in 1984) Supreme Court verdicts and *case-law*, our history has helped enormously to realize a practice of doctors complying with euthanasia requests of their patients without fear for prosecution (if having met with the juridical formulated criteria) as early as 1984. In a time when a State Committee (Rommelink, 1985) gave a clear and transparent description of the issue, definitions included and as a follow up the execution of a large *survey* amongst Dutch doctors (1990) into the (f)actual practice.

Another positive contribution to the Dutch development was the open *support given by the Royal Dutch Medical Association (KNMG) and later political parties* (mainly the liberal democrats of D66).

All this resulted in a situation where – when in April 2001 the Dutch Euthanasia Law (after introduction by minister Els Borst, August 1999) was finally approved by the Parliament, and implemented in April 2002 – the practice for Dutch doctors did not change dramatically, the law being a codification of a grown, tolerated and juridically tested practice of more than 20 years. This can be called a bottom-up development.

Unfortunately, other countries and jurisdictions that cannot profit from the Dutch assets (history, culture and support), will have to turn to practically top-down developments: private member’s initiatives and bills. Thus is the use of foreign experience, certainly when available, important.

The debates in practically all countries, as it did in the Netherlands in the 80-ies, revolve around safeguards to prevent misuse and abuse and guarantee safety for individuals (the vulnerable): proponents want as few as possible (choosing for autonomy and human right as leading principle only reluctantly accepting physician involvement), where opponents suggest that never enough safeguards will guaranty safety for specific vulnerable groups.

You will have noticed that a majority of the submissions against based their argumentation on a number of returning data, many of those derived from the Dutch research and surveys.

With me many others find the way these figures are used better is declared as (deliberate?) misuse of the figures on the end-of-life practice in the Netherlands. These figures are mostly found in the large scientific Dutch Surveys, and produced since 1990 (Rommelink Report) regularly scientifically sound (world renowned statistically) figures about the end-of-life practice in the Netherlands. These surveys are repeated more or less every five years, in 2015 for the last time.

One of the *misconceptions* is that in the Netherlands old and incapacitated people are afraid of going to hospitals or nursing homes. Sometimes it is even reported that people carry “credit card sized” cards saying that they do NOT want euthanasia (I have never seen one!).

It can be proved that this interpretation is wrong: the facts below are the number of (reported) assisted dying cases in that year.

*'Facts'*

- Onwuteaka e.a. (2005):
  - 2125 at home (= > 80%)
  - 225 in hospital
  - 75 in nursing home
- Review Committee (2013):
  - 3800 at home
  - 240 in hospital
  - 428 in elderly/nursing home
  - 295 in hospices

< 20% of all assisted dying is taking place in hospitals or nursing homes. As in most countries around the world, people want to die at home!

These figures include amongst others also figures on doctor’s actions at the end of life of persons, which are against our law then as now (the number of cases of *life-termination without request*, happily misused by opponents); but, these figures have decreased by some 75 % since our law was put into force.

*'Facts'*

Termination of life without request:

1990	0,8% (=1000 of 'Rommelink')
1995	0.8%
2001	0.7%
2005	0,4%
2012	0,2%

In many countries now *Palliative Care* (PC) in general and Palliative (terminal) Sedation (PS) in particular is brought forward as alternative to euthanasia or medically assisted dying. But Euthanasia and PS are two different possibilities at the end of a process of dying guidance / palliative care; each has its own properties, the one never can be replaced by the other as if they are full alternatives.

The suggestion that the availability of good PC would prevent having to provide Euthanasia can be falsified by the list below, where you can see that the main reasons to ask for Euthanasia are not or very difficultly to be dealt with by PC.

## 'Facts'

### Reasons to ask for euthanasia:

- meaningless suffering 65%
- deterioration 44%
- total weakness 43%
- prevention of deterioration 36%
- dependence 33%
- *pain* 29%
- *suffocation* 23%
- being a burden to others 27%

In recent research about the quality of PC in European countries by the EAPC, it has been seen that the Netherlands is now in the top (5<sup>th</sup> place) of countries concerning Palliative Care. PC has been incorporated in the “normal” health care system and is therefore generally financed from the basic Health Insurances.

### The slippery slope

The frequently heard argument of a slippery slope is in my opinion not proven to be true: our numbers make clear that such a slope is not existing. If there is one country in the world such a slope would be happening, it would be the Netherlands; no country in the world has a longer existing practice of tolerated and legalised practice (now over 35 years)

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*> 35 years of Dutch tolerated and legalised medical aid in dying (euthanasia and PAS) practice shows no sign of a slippery slope*

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The threat of misuse (“once doctors are used to terminating life *on* request, they will start doing it *without*) has already been falsified; if we look at the illnesses and diseases for which requests are made, we do not see changes in the general pattern, still a majority of cases concern (terminal) cancer (85%); the rise in numbers for more complex situations like dementia and psychiatry are only marginal – even stabilized last year.

### Final remarks

Finally, I want to emphasize that medically assisted dying is to be considered as the final step in a longer process. An initial request seldom is made “out of the blue”, patients are ill, diagnosed and in treatment and thus “seen by doctors”. After that request there should be ample time to talk with patient and family; to try and make the suffering bearable, offering alternative treatments; so time enough “to grow” as doctor and patient “together” to the moment where the suffering is unbearable, because no longer treatable. And do not forget: patients do not easily put such a request to their doctor, and doctors generally are not eager to terminate a life – rather try and find other options to deal with the suffering of the patient.

More than 30% of all requests are not complied with because the patient dies before the assisted dying has to be performed: patients in the end can endure more suffering than they thought in the beginning. In this way a promise to assist if the really is intolerable is rather prolonging life, than that it is shortening it.

One of the positive spin-offs of the Dutch laws has been the professionalization of the lawfully required “second independent doctor”: these doctors are now known as *SCEN-doctors* (**S**upport



and Consultation with Euthanasia in the Netherlands). These trained consultants turn out to be (if not the) major factor in guarding the quality of the Dutch Euthanasia practice. Though not legally required, practically all euthanasia-cases that are reported – and those are representing more than 85% of all cases in NL – have been receiving a SCEN-doctor's advice.

Including a sort like scheme in New Zealand (appropriately called SCENZ) is a great improvement and in my opinion another guarantee against misuse.

To summarize:

1. People in The Netherlands (as in New Zealand) rather live than die, but want to have (and in The Netherlands now are lucky to have) the possibility to ask for medical support when they find the end of their life is inhumane because of futile suffering.

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*Medical aid in dying should be considered as an act to end suffering and not specifically as one to end life*

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2. The Dutch have since the legalization seen no increase in numbers, no increase in misuse (if at all in substantial numbers), no decrease in trust in doctors and all that despite internationally recognized high level of Dutch palliative care! A human being does not ask easily for help to die; the legal possibility to do so facilitates the asking, facilitates the civilized conversation about this last phase of someone's life and – in my experience – sooner prolongs life than shortens it; prevents ill-considered decisions from desperate humans and leads to better end-of-life care for all, palliative care included!

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*Availability of medical aid in dying sometimes prolongs life rather than shortens it*

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3. In no country in the world there is so much openness on medical decisions around the end of life as in the Netherlands. The scientifically well renowned reports of 1990, 1995, 2001, 2005 and 2012 (Rommelink, Van der Wal, Onwuteaka) are statistically sound and show no signs of a slope downwards, let alone a slippery slope:
  - i. the absolute numbers of euthanasia and physician assisted suicide have shown to be rather stable, being some 2% of all death cases per year; the percentage of *reported* euthanasia cases has grown from 18% in 1990 to some 80% in 2012;
  - ii. the same reports even showed the decisions without requests (also in our eyes to be incorrect!) also to dramatically go down from 0,8% in 1990 to 0,2% in 2012 (some of them being termination of the life of severely multi-handicapped new-borns)
  - iii. since 2001 there was a significant rise in percentage of Palliative Sedation (PS), a development in the opposite direction of that of Euthanasia.
4. Even the best of Palliative Care (PC) will never be able to take away all requests for euthanasia. The best PC offers a free choice to patients as to how and when they die. One of those should be Euthanasia, another PS. Good communication between the dying patient (and his/her family) on the one side and the acting doctor on the other side, long before the

final moments turn out to be crucial for a humane death for the patient and a soothing bereavement for the relatives.

5. The lessons from the Netherlands can be that legalisation of Euthanasia turned into a better quality of all end-of-life care, a higher level of Palliative Care and a continued high level of trust between doctors and patients.

Now, as WF Executive Director and as webmaster of its website [www.worldrtd.net](http://www.worldrtd.net), I regularly see all those false arguments reappear, and my big fear is that wrongly used statistics from The Netherlands might be the reason for NOT accepting your End of Life Bill, and advising against the development of a law that would be safe for misuses, and merit the wishes of a lot of suffering New Zealanders. It has showed in the Netherlands to be in the interest of patients to have real choices at the end of life. Choices like that will be only possible where and if a legalized possibility is in existence.

Knowing the complexities in this and realizing the limitations of written evidence, I will be happy to give oral evidence on the matter in a discussion with your Committee if they see the benefits of such evidence.

Rob Jonquiere, MD – Executive Director WFRtDS

## Do you call that a life? Active euthanasia and physician assisted suicide in the Netherlands

*As a Dutch journalist, I have written several books and articles on euthanasia and physician assisted suicide and its wider consequences for society. I have participated in many debates in Dutch and German television and radio shows. One of my books is available in English, 'Do You Call This a Life? Blurred Boundaries in the Netherlands' Right-to-Die-Laws', London (Canada), Ross Lattner, 2015.*

The Netherlands changed profoundly since active euthanasia and physician-assisted suicide were legalized. The way people cope with suffering, and, more importantly, with people who are suffering, is no longer as it used to be.

It all looked so easy in the beginning.

The debate about euthanasia and physician-assisted suicide started with examples of competent people who were in pain and demanded euthanasia or physician-assisted suicide. I'd like to call these the classic cases of euthanasia or physician assisted suicide.

It always starts with these classic cases. Every debate about right-to-die laws starts with the more obvious and easier examples. This was how it started in the Netherlands. And this is how it starts today in other countries where physician-assisted suicide and euthanasia are being discussed.

These same classic cases are the ones that are mentioned in the media, in movies, in debates about euthanasia and physician-assisted suicide. They are the examples that are easy to understand, even if you're not yet convinced that right-to-die laws should be enacted.

In these debates the main argument for right-to-die laws is the autonomy of the individual. Someone who is suffering should be able to decide for himself if he wants to live or prefers to die. Autonomy is indeed an essential value in our western societies. Where we live, what we do, whom we love is up to us. And so it seems

only logical that we should also have the right to decide for ourselves when we die. The patient who has a good reason for wanting to die, should not be left out in the cold; physicians should have the right to help him die with dignity.

In the Netherlands, a physician has the legal right to administer a lethal dose of drugs to a patient who suffers severely and who demands to die. If the patient takes these drugs himself, it is called physician-assisted suicide, if the physician injects the drugs, it is called euthanasia. Both are legal in the Netherlands.

Euthanasia is only legal if the patient explicitly demands it. Without a patient's request, euthanasia is murder, as it was stressed initially in the Netherlands and today in other countries where right-to-die laws are being discussed.

However, in the Netherlands, euthanasia practice did not remain limited to the classic cases of competent patients who are suffering. As soon as euthanasia was made legal by the highest court, the next debate started.

For instance, incompetent patients also suffer. If uncle Harry can demand euthanasia when he becomes ill, should his nephew Garret really continue to suffer when he is in trouble, just because Garret is mentally retarded? If aunt Monica can demand euthanasia when she falls ill, should her niece Catherine really be forced to endure pain, just because Catherine is a child?

The idea that it is feasible to limit euthanasia to competent people, has turned out to be unrealistic. If you accept that suffering can be alleviated by terminating the patient's life, it is not easy to define new limits. At least in the Netherlands we are still looking for the new limits.

After more than 30 years of experience with euthanasia and physician-assisted suicide in the Netherlands, there is no unambiguous conclusion. There seems to be a sunny side, as well as a dark side.

The positive side is represented by the thousands of uncontroversial cases where patients get euthanasia at their request and, only in a minority of cases, physician-assisted suicide. Almost 4 percent of the people who died in 2015 in the Netherlands died from a lethal dose of drugs administered or handed to them by a physician for the purpose of terminating their lives. These cases were almost always reported, the reported cases were reviewed by review committees that rarely found irregularities. Most of these cases involved cancer patients with limited life expectancies who died at home with the help of their general practitioner.

These are the classic euthanasia cases, they do exist and they can be monitored by the relevant authorities. These are the examples that my fellow countrymen like to refer

to when they present lectures abroad about this gem of Dutch society. This does not mean they tell lies; the vast majority of cases where people's lives are being terminated are in accordance with the law.

However, there also is the less easily controlled and only semi-regulated practice of termination of life without request, or non-voluntary euthanasia. Legally these cases are based on the defence of necessity: in emergency situations and under certain conditions a physician is allowed to do things that he is normally not allowed to, namely to terminate the lives of his patients without request. Necessity is, in continental law systems, a principle of defence that can be seen as a safety valvet in criminal law. In the Dutch euthanasia history, this defence of necessity has played an essential role. Before the Euthanasia Act of 2002, euthanasia was already performed, but on the basis of the principle of necessity. According to the Dutch High Court, physicians sometimes faced an emergency where the duty to relieve the patient's suffering and the duty not to kill collided. In such emergencies, euthanasia and physician assisted suicide could be defended as necessity. In the case of termination of life of ill or disabled babies, the development has been similar. Since 2005, there

is an official guideline for pediatricians, formulated with the help of the Public Prosecution Service, that lists the criteria for termination of life of severely suffering babies. According to criminal law, this is illegal, but in emergencies, courts do consider the defence of necessity when the criteria of this guideline are met.

In 2010 there were about 300 cases of termination of life without request in the Netherlands, before there were up to 1000 cases of termination of life without request per year in the Netherlands. We know this thanks to an anonymous survey amongst physicians that is being repeated every five years. The number is based on an extrapolation.

What is going on in these cases of termination of life without request?

We do not know exactly, as most of them are not reported. Some have been reported to the Public Prosecution Service though, especially a number of cases concerning severely disabled or ill infants.

Like the son of a father I interviewed, who had been born with spina bifida. In the year 2003, the father agreed to have the life of his baby son terminated. The baby was transferred to the Groningen University Hospital, where the doctors told the parents the prognosis. Their boy would require many operations and he would probably have to live in an asylum for the disabled. Trying to imagine what kind of life was

awaiting his son, the father realized that he wouldn't be able to endure such a life himself, so he couldn't demand that his son did, he explained to me. The parents and the physicians agreed that it was better to terminate the life of this boy. Between 1997 and 2004 pediatricians reported 22 cases of termination of life of infants with spina bifida in the Netherlands. The Public Prosecution Service choose not to press charges against the involved pediatricians, considering the defence of necessity.

These instances of non-voluntary euthanasia, that jeopardize the image of euthanasia as a symbol of the autonomy of the citizen, are not very controversial in the Dutch media, in parliament or in medical associations.

More important than the figures, however, is the mentality, or the way people think and talk about illness and disabilities, and about ill and disabled people. In the media, there are many debates about life that is marked by severe disabilities or disease. Typically, the question that pops up in these debates is whether these lives are still worth living, or would death be a relief?

The motivation for this way of thinking is utterly humanistic. The ideal is that every human being develops his or her human potential, that every human will be more developed tomorrow than he is today. This also goes for people who are challenged by disabilities or disease; they are entitled to support to develop themselves as much as their fellow-citizens. The Dutch welfare system is lavish compared to most other countries; everybody is given a chance to develop himself, no matter what it takes.

There are people, however, who are so ill or so severely disabled that, regardless of the effort, they will remain unable to develop themselves. All you can do for these people is take care of them.

The Dutch reaction to these cases appears to be one of desperation.

Or to quote a mother who talked about her daughter with multiple disabilities on public television: "She knows nothing, can do nothing, she really is nothing."

This is the paradox of the high-quality care in the Netherlands: we have such lofty ideals about being human that we are not satisfied when, despite our best care, a person does not live up to those ideals. And then we start discussing the worth of his or her life, then we start thinking of

death as a relief. In this way an idealistic image of humankind and good care can go together with a people-threatening practice.

I just quoted a mother who said about her disabled child: “She knows nothing, can do nothing, she really is nothing.” This mother has an agreement with her daughter’s

physicians that they will not treat life-threatening illnesses and she has confessed she is waiting for the moment that such an illness will present itself: no antibiotics for the disabled child. What is most striking is not that this mother is desperate and this is her decision, but that there was no public outcry in the Netherlands as she said this on national television.

We seem to have lost the sense of equanimity that allows us to accept forms of life that seem to be pointless. The Dutch want to do something, they want to act and find solutions. It is these activist, humanist ideas about mankind that foster a debate about euthanasia and termination of life: life must be worthwhile and when it is not, we must do something about it.

And still the debate goes on.

Many citizens in the Netherlands are now trying to broaden the scope of the euthanasia law. Today, they try to help people who are, as they call it, ‘done with life’. This latest expansion of the Dutch euthanasia debate focuses on elderly people who see no reason to go on living and who long for death. If death does not come, they should be assisted in ending their lives.

Assisted suicide is already permitted under the Dutch Euthanasia Act, but only when carried out by a physician in the case of severe suffering. The step advocated now would also make assisted suicide an option for people who are not experiencing hopeless and unbearable suffering, but who have reached their seventies and feel they have lived long enough. Specifically designated healthcare professionals should be available to help these people die.

Two proposals for assisted suicide are now being formulated. One political party proposes to enable assisted suicide for people over the age of 75, another party proposes to enable such help for people of all ages who are tired of life. Both proposals will be discussed in the coming years.

Dutch physicians have not rejected the idea of assisted suicide for elderly who are weary of life out of hand, but they did not welcome it either. KNMG, the Royal Dutch Medical Association, advocates a middle course and argues that anyone who is elderly and weary is suffering from some degree of geriatric affliction which can, with some effort, be regarded as ‘hopeless and unbearable suffering’.

There are indeed cases that have already been approved by the euthanasia review committees that monitor compliance with the Dutch Euthanasia Act. Many requests for assisted suicide from elderly persons who are ‘done with life’ can therefore be met within the boundaries of the Euthanasia Act, without the need for amendments.

This shows how flexible the Dutch euthanasia law really is, and how flexible the words ‘hopeless and unbearable suffering’ are.

Then there is another debate, about euthanasia for children. The law allows euthanasia for children aged 12 years and older, when their parents and the children themselves agree.

And termination of life of severely suffering babies has been regulated in 2005, as mentioned. Eduard Verhagen, the same physician who helped formulate these regulations for termination of life of severely suffering newborns, now proposes to move on and also regulate the termination of life of severely suffering children between the ages of one and twelve years old. His argument is that children older than one year old can obviously suffer as well.

This example shows that it is indeed difficult to limit termination of life to competent patients who demand to die. As soon as the principle is accepted that under certain conditions severe suffering

may be ended by ending the life of the patient, it is difficult to stop the practice and limit it to a certain category of patients.

Then the fate of patients with Alzheimer's disease was debated. Due to the disease, the patients can become incompetent over time. According to the law, they can get euthanasia if they drew a living will before they became incompetent. However, physicians in the Netherlands prefer to act not only on the basis of a last will; they want to hear the patient repeat the wishes included in that will. Until recently, euthanasia or physician-assisted suicide, were indeed only carried out in the case of patients who were still competent, in other words, at the early stages of Alzheimer's disease. Recently, however, the euthanasia review committees have approved cases of patients with advanced Alzheimer, who could not repeat their earlier wish to die but whose lives were ended by their physician on the basis of their earlier stated wills. This means that we are not entirely sure whether these patients were still aware of their wish to die on the day this wish was about to be realized.

In 2015, dementia (in different stages) was mentioned in 109 cases of euthanasia or physician-assisted suicide that doctors reported to the review committees.

Another category of patients that is being debated today are mentally ill people. For a long time, psychiatrists in the Netherlands were unwilling to help their patients die because their competence was potentially affected by their psychiatric disorders. The patient's wish to die can be a symptom of their psychiatric disorder. Psychiatrists have been criticized for this unwillingness, which has been explained as a denial of the right to self-determination of patients with psychiatric diseases. Recently, a small number of cases of euthanasia or physician-assisted suicide has been reported by psychiatrists. These were cases where they thought that there were no therapies left to help their patients. In 2015, psychiatric disorders were mentioned in 56 cases of euthanasia or physician-assisted suicide that were reported to the review committees.

Then there are some random cases that have caused a stir recently. There was, for instance, the story of a woman whose life was terminated because she suffered from a severe form of tinnitus, or bustling in her ears.

Or the story of a civil servant with a long history of depressions, 63 years old, who was very lonely and couldn't face his retirement. Both the woman suffering from a severe bustling in her ears and the lonely man who was about to retire got the help they were looking for from the so-called 'end-of-life clinic'.

This clinic in The Hague is an initiative of the Dutch right-to-die movement NVVE. This is where patients whose own doctors refuse to help them to die get a second chance. The end-of-life clinic disposes of more than 30 mobile teams that help patients to die at home. This end-of-life clinic aims to work strictly according to the law. However, some cases it reported have already been rejected by the euthanasia review committees so far.

From euthanasia in the classic sense to termination of life in newborns with spina bifida, is unmistakably a considerable development. The road from assisted suicide because a person is in pain as a result of cancer, to euthanasia because a person is lonely and weary of life or suffering from a severe ringing in her ears is also quite impressive.

It's up to you to judge this development. You may be of the opinion that it is a disgrace that the position of the Netherlands has shifted this far, you can also be of the opinion that in all of these cases termination of life is the best of the available options, is indeed the lesser evil. The one thing you cannot do is deny that the boundaries are continually pushed back, moving the Netherlands a considerable distance from its original position. The discussion about one category of people for whom termination of life is suggested draws attention to an adjacent category of suffering

individuals that the same arguments for termination of life can be applied to. And so the position of the Netherlands is shifting. Again, we need not consider this a disgrace. But the shift itself cannot be denied.

Making euthanasia and physician-assisted suicide legal started a development we did not foresee. The old limit 'thou shalt not kill' was abandoned, a new limit is yet to be found.

This drawback of the euthanasia practice, the cases that are more difficult to legitimate like the termination of life of severely disabled babies, is less frequently mentioned. Nor is there much debate about the shift towards ever new categories of patients for whom euthanasia is proposed.

No wonder, the number of lawful cases of euthanasia or physician-assisted suicide vastly outnumbers the controversial cases of termination of life without the request of the patient. Many Dutch people have experienced the more classic forms of

euthanasia or physician-assisted suicide in their own families or among their own friends. The majority of these cases concerned patients who were suffering from cancer and could die at home with the help of their general practitioner. This is seen as something very positive by most people. Opinion polls show a vast majority of citizens who support the euthanasia law in the Netherlands today. Most Dutchmen think of the euthanasia law as a good thing, something they want to recommend to the rest of the world.

Being a proud Dutchman myself, I was one of those eager to recommend the Dutch euthanasia law to the entire world twenty years ago. I'd like to tell you why I started asking questions.

In January 1996, surgery was performed on my partner's brain because of a tumour. The operation failed, his brain was severely injured afterwards. He lived another ten years, crippled, confused and with a character that had changed. I loved him nevertheless.

It was a shock to hear friends question whether his life was still worth living. 'He would have been better off dead', was what one of his friends said. Another friend said to him: 'It's your choice to continue living, so stop complaining.' He hardly ever complained by the way, but this remark shows that living with a disability can now be seen as a choice,

not as a plight.

These remarks were a kind of wake-up call for me and I started to write articles about how people in the Netherlands not only judge the worth of their own lives, which is in line with the Euthanasia law, but also the lives of other people. It was to be expected that people think: 'I would not want to live on if I were in her position', or: 'I would prefer to die if I were like him'. These opinions are then projected onto the people who are in such a difficult position. According to Dutch law, you have the right to demand your own death if you feel that your life has become unbearable. People confound this with the right to make judgements about the quality of the lives of others, which we should not judge at all.

You can think of the Netherlands as a laboratory. The Dutch experience can help you to understand what might happen in the future once you enact right-to-die laws.

Gerbert van Loenen

## Palliative care or assisted dying? We just need to start talking more about 'the right to die well'

Published on: April 11, 2016 Author: David Clark

In most parts of the world the proponents of palliative care and of assisted dying do not see eye to eye. Palliative care activists say the problems that lead to assisted dying requests can usually be

dealt with in ways that do not hasten death. They promote quality of life and reject the idea of “dying on demand”. Supporters of assisted dying, on the other hand, argue that palliative care cannot be effective in every case. To them, the important thing is to respect autonomy and freedom of choice.

It’s unclear whether these two approaches can be reconciled.

Relations between supporters of palliative care and of assisted dying have a history of tension, even antagonism. Dame Cicely Saunders, founder of the modern hospice movement, was fond of going head-to-head in debates with members of the Voluntary Euthanasia Society in the 1960s, for example. More recently, the society’s change of name to Dignity in Dying in 2006 antagonised the hospice and palliative care world by implying that its practitioners did not have the monopoly on a dignified end.

Just last year, a group of experts representing the European Association for Palliative Care again declared that the provision of euthanasia and assisted dying should not be included in the practice of palliative care – a position that has remained unchanged for the last two decades.

The British Medical Association likewise remains opposed to the legalisation of assisted dying in any form, though in a series of recent reports it said it now seeks “to move debate beyond oversimplistic for/against positioning to consider some of the complex issues surrounding physician-assisted dying, its potential complexities and changing legislative and practical frameworks”.

Over the years, however, palliative care has struggled to gain traction. Indeed, my own research has shown that just 20 countries in the world have achieved “advanced integration” of their palliative care services with the wider health and social care system.

Palliative care physician BJ Miller discusses what really matters at the end of life for TED Talks.

The UK is ranked the best place to die when it comes to palliative care, according to an index constructed by the Economist Intelligence Unit (EIU). But there have been obvious failings and shortcomings in the delivery of palliative care at scale. We see these in the furore over the Liverpool Care Pathway and in poor reports on end of life care from the ombudsman and the Care Quality Commission.

Would legalised assisted dying have any bearing on these problems? We only have a few examples to go on.

### [Legalising assisted death](#)

Euthanasia and/or physician assisted dying are currently legal in just four countries: the Netherlands (2001), Belgium (2002) and Luxembourg (2009) have all legalised euthanasia. This means it is legal in these countries, provided certain procedures and protocols are followed, for a doctor to kill a patient at their informed and competent request.

In the US, individual states have focused their efforts on the legalisation of physician assisted suicide, though the broader term “aid in dying” is now being adopted by some. This involves a doctor in a process to prescribe lethal drugs to a person who, following defined procedures, has resolved to end their own life by taking the drugs, and then does so. It was legalised in Oregon in 1997 and more recently was taken up by Washington State, Montana, and Vermont. California will soon follow when its End of Life Option Act comes into effect on June 9.

By long standing arrangement, Switzerland does not prosecute those who assist a suicide, provided they do not benefit from the outcome.



In locations where either physician assisted suicide or euthanasia are legalised, there is no evidence this inhibits the development of palliative care. In Oregon, most of the very small numbers of people who avail themselves of the Death with Dignity Act are actually on hospice programmes. In the Netherlands, palliative care services, research and education appear to have thrived in the period since euthanasia was fully legalised, though they were underdeveloped before that.

Belgium provides the most interesting example: it has almost 200 palliative care services, is in the list of 20 countries with “advanced integration” of palliative care and was ranked fifth worldwide in the EIU’s “quality of death” index. It is also home to academic research groups studying end of life issues as well as leading professors in the field – yet in Belgium about one death in 20 results from euthanasia.

### The Flanders model

Something unique has happened in the Flanders region of Belgium: the practice of euthanasia and the delivery of palliative care have been brought together in a single “integral” model. Here no contradiction is seen delivering the best pain and symptom management and the holistic psycho-social support that palliative care has to offer, while also enabling a person’s life to be ended at their request, by a physician.

The Flanders model offends some and inspires others. But, as the authors of one of the few studies on the matter conclude:

Most values of palliative care workers and advocates of euthanasia are shared. If Belgium’s experience applies elsewhere, advocates of the legalisation of euthanasia have every reason to promote palliative care, and activists for palliative care need not oppose the legalisation of euthanasia.

Should assisted dying and the delivery of palliative care exist side by side? Their shared aim would be to provide relief from suffering, support dignity and also allow the freedom to determine the manner and timing of one’s own death. Flanders and Oregon hint that this approach can work, and we intend to look at this further in our Wellcome Trust-funded study on Global Interventions at the End of Life.

It is perhaps time to bring down the ethical and ideological wire fence which has for so long separated the two approaches to the end of life: palliative care and assisted dying. Once this barrier has been removed we might more fully explore how best to deliver dignity and choice to the growing number of people who will die in the world every year.

*David Clark, Professor of Medical Sociology, University of Glasgow*

*David holds a Wellcome Trust Investigator Award and leads the Global Interventions at the End of Life research project. He is founder of the Glasgow End of Life Studies Group.*

*This article was originally published on The Conversation on 30 March 2016. Read the original article.*

*Subsequent to writing this piece the author has learned that euthanasia has been practised legally in Colombia since 2015.*

# Part Five: The Stories

## 16000 Voices

16000Voices was a campaign established in response to Hon David Seymour's EOLCB. The website was launched Wednesday, 8 March 2017 but has recently been decommissioned. Nevertheless, many of the stories told on that site are still available as below:

Isaac's Story	Autism and Epilepsy	<a href="https://www.youtube.com/watch?v=ySXoxr2_bSs">https://www.youtube.com/watch?v=ySXoxr2_bSs</a>
Dion's Story	Mental Health Nurse	<a href="https://www.youtube.com/watch?v=L626iRwod0E&amp;t=8s">https://www.youtube.com/watch?v=L626iRwod0E&amp;t=8s</a>
Maria's Story	Intensive Care Nurse	<a href="https://www.youtube.com/watch?v=9KsffHrI0GM">https://www.youtube.com/watch?v=9KsffHrI0GM</a>
Stephen's Story	Law Professor	<a href="https://www.youtube.com/watch?v=rDrW-mC94cc">https://www.youtube.com/watch?v=rDrW-mC94cc</a>
John's Story	Disability Activist	<a href="https://www.youtube.com/watch?v=wQWGvxVfjCM">https://www.youtube.com/watch?v=wQWGvxVfjCM</a>
Narelle's Story	Journalist	<a href="https://www.youtube.com/watch?v=f4Y9I6wLcyQ">https://www.youtube.com/watch?v=f4Y9I6wLcyQ</a>
Ralph's Story	Cancer Doctor	<a href="https://www.youtube.com/watch?v=7RO8cz8heBk">https://www.youtube.com/watch?v=7RO8cz8heBk</a>
Clarion's Story	Banker (Brother with MND)	<a href="https://www.youtube.com/watch?v=nfvt7S2p_tQ">https://www.youtube.com/watch?v=nfvt7S2p_tQ</a>
Linda's Story	Medical Lawyer, Feminist Activist, Hospice Volunteer	<a href="https://www.youtube.com/watch?v=fkyhWZ8J7vA">https://www.youtube.com/watch?v=fkyhWZ8J7vA</a>

## Submissions to Select Committee

Many of the submissions made to the Select Committee included the personal accounts of people living with terminal illness. We have included a small sample in the following pages.

### Nurse - February 2018

I support the passing of the End of Life Choice Bill as it would give people in NZ with a terminal illness or who are suffering from a grievous and irremediable medical condition the option of requesting assisted dying when they are experiencing intractable intolerable suffering.

I am now a retired nurse with 52 years of nursing experience. During my career I worked in both the clinical, management and in nursing education. The last 5 years of my career I spent working in a Hospice providing palliative care.

Throughout my life and while nursing I have been involved with the deaths of friends, family and patients. It is these experiences together with researching international literature on physician assisted dying (PDA) end of life care, palliative sedation, assisted suicide and euthanasia that has influenced 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 and intractable, despite palliative care interventions. I would like to have the ability to request help to die and be released from this suffering.

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

During my life, I along with everyone who lives make choices every day related to how we live, take care of ourselves and our families.

I have and continue to make choices for example. Choices about my personal life, where I live, my career, my marriage of 52 years, my family, what I eat, how I spend my time, how I take care of my health, the list goes on and on.

In regard to my health: at this time I am 72 years of age, I feel filled with health and vitality with a great deal to look forward to.

So, if I have a headache, my options are, do nothing or if I am not great I take 2 paracetamol to relieve my suffering cause by the headache.

When I injured my shoulder slipping down a hill last year I sought medical attention as I was in pain. A few days on anti-inflammatory medication and pain relief my pain was relieved.

This is just what we do as people; we find ways to relieve suffering. No one that I know wants to suffer if a solution to relieve this can be found.

I believe we have a right to expect that we can have help to end our life if our suffering is unable to be relieved.

At Hospice most patients were helped with support of the palliative care team, with appropriate interventions and pain management. When death came it was a more peaceful death.

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 some experienced intolerable intractable pain. Using a range of treatment options suffering was not relieved allowing them to feel at peace.

Some patients were in the terminal stages of congestive heart failure and those with Motor neurone disease struggling breath are just two conditions this Bill would enable to have an option if they wished for a peaceful end of life to their life.

Many patients at Hospice would ask me and other staff members *"please help me die"*

Or *"can't you just give me something so I can go to sleep and not wake up"*

Or *"I have suffered enough, please someone help me."*

For some patients, palliative sedation was initiated. This is patients being given increasing amount of Morphine or Midazolam for example to totally sedate them. At that time food and fluids were stopped. Death from their condition or dehydration follows within hours or days. Palliative sedation is not a treatment that I would wish to have done to me.

Is this not a form of physician assisted dying by another name? Doctors and nurses want to relieve intractable suffering.

International palliative literature and NZ End of Life care research supports the fact that not all suffering is relieved by palliative care interventions.

Further reading I recommend is the book, **Dying Badly – New Zealand Stories**. My submission to the NZ Health Select Committee on Physician Assisted Dying has been included in the book. In this I describe the death of my nursing friend who despite palliative care did not have a peaceful death. Many other stories are about parents, family members and friends dying agonising distressing deaths.

This current Bill has included guidelines for patients making a request to have assistance to die, a very clear and comprehensive process for medical practitioners, medication choices, care when dying, care of unused medication, the after care of patient and legal requirements.

This is vitally important to safe guard the potential for coercion of vulnerable people.

My final key points:

1. Scientifically conducted opinion polls recently held in NZ shows that at least 75% of New Zealanders believe that this is a right in a modern civilised society.

2. Thousands of people explained why they believed this in submissions to the Health Select Committee.
3. People die agonising deaths every week in NZ. Some experience intolerable suffering for years, some for months and some for weeks. Let NZ have a compassionate approach and allow people with a terminal illness with only months to life a chance to have merciful relief from their distressing disease symptoms.
4. Many countries have implemented legislation supporting physician assisted dying throughout the world. Oregon USA has had VAD for 20 years with strict guidelines and have demonstrated that the elderly and disabled are not at risk.
5. Physician Assisted Dying happens in NZ already through palliative sedation.
6. Only a small percentage of terminally ill patients seek to have assistance to die. Please refer to international research data.
7. If those with religious beliefs hold the view that this is morally wrong they will obviously make the choice to cope with intolerable suffering before dying.
8. I see no reason that people holding religious objections to physician assisted dying should deny others who don't share this belief the right to have a peaceful death if suffering from a terminal illness has become intolerable to them.
9. I am a Christian.
10. I totally support this Bill being passed into NZ Law.

### Myeloma Sufferer

My story, in the context of this submission, began seven years ago when I was diagnosed with an incurable form of bone marrow cancer called **myeloma**, where plasma cells undergo malignant change and become myeloma cells, which multiply without any proper order, forming tumours that accumulate, mostly in the bone marrow and on the surfaces of bones in the body.

Treatment over the past seven years has included two autologous stem cell transplants, numerous chemotherapy cycles, and many referrals to pain clinic followed by radiography to repair excruciating bone tumours. Chemotherapy has resulted in ongoing compromised immunity, meaning I am often susceptible to infection. I've been hospitalised for acute pancreatitis and shingles, and been given many many blood transfusions and regular bone-strengthening infusions. Cruel muscle cramps, especially at night, and painful peripheral neuropathy which affects nerve-endings in my feet and hands, are just some of the side-effects of chemotherapy.

Living with myeloma can best be described as a roller-coaster ride. When remission ended for a third time in late 2014, two new chemotherapy treatments were trialled. Each failed to control the cancer. From March to July 2015, a third treatment succeeded, but ended in a disastrous bone marrow malfunction. As a result, further chemotherapy has had to be abandoned. Since then my life has centred on emergency admissions to hospital, and blood tests up to three times a week.

Physical pain (primarily in spine and pelvis) has been, and continues to be, energy-sapping. For seven years morphine and other prescription drugs have been used to mask the pain, but have an enervating effect, meaning I am always tired. Recently when my morphine dose was doubled in an attempt to more effectively subdue my pain, it didn't work. Instead it numbed and dulled my brain, a horrible zombie-like and not-to-be-repeated episode.

Whilst numerous medical interventions have lengthened my life, they have now been exhausted, and I endure a life with very little quality, a kind of half-life. I exist. I no longer have the energy to

participate in activities that have always brought joy and meaning to my life, and I'm becoming increasingly dependent on others for assistance with minor everyday tasks.

I do not feel depressed or despondent, and I gratefully acknowledge that I have received the best haematology treatment our health service can provide. But I have now reached the stage where, having exhausted all available forms of medical treatment, my body, my organs and my bones will start to break down. My bone marrow will no longer be capable of making new blood, and painful tumours will corrode my bones, causing them to fracture or break. My kidneys will 'silt-up' and cease to function.

I have lodged an **Advance Directive** with my GP, the DHB and Hospice, and have given copies to my daughter and son. My children are wonderful and caring, but seven years of watching their mother undergo gruelling and invasive medical treatment has given them an appreciation of my reasons for wanting to decide when and how I die. As you can appreciate, I am not the only person affected by my suffering.

Naturally, my dream is to die a gentle, peaceful death, surrounded by my family and dearest friends. The reality is that I don't know what kind of death I will have. To end my life in a medically-induced coma would be a humiliating, degrading, drawn-out way to die, and would be absolutely gruelling for my daughter and son to watch.

In the absence of legalised voluntary euthanasia, I can, under current law, legally refuse food and hydration, and I can request maximum palliative sedation, but I cannot ask for and be given medical assistance to die. **Why not?**

Legalised voluntary euthanasia, PAD, would give me that choice.

### **1. Factors that contribute to the desire to end one's life**

**Unbearable suffering would be, for me, the most compelling reason for wishing to end my life. This could be pain that cannot be controlled, or simply feeling that I have suffered enough.**

It's wrong to think I want to end my life. I enjoy life, and I don't want to die, but the cancer is killing me, and I am dying. I would like to be able to choose a conscious and peaceful death. But, under our present law, for me this is not an option.

I do not want a prolonged, agonising death. Bone cancer, despite best efforts, falls into a category of pain that cannot always be controlled. In 2011-12, I experienced excruciating bone pain that I can expect again when bone tumours recur in future.

Nor do I want terminal sedation. To spend my last days in a medically induced coma, being drugged into an unconscious state, is abhorrent to me, and I don't want my daughter and son exposed to this kind of pointless, drawn-out and degrading spectacle, but realistically, this is what I can expect.

If PAD were available to me now, I may elect not to use it, but I would like to have the choice.

Without legalised PAD, I do not have that choice. Knowing I could have physician assistance to die when my suffering became intolerable would give me immense peace of mind.

**Continuing loss of my bodily functions and increasing dependence on others for personal care are for me a distressing, humiliating and pointless prospect.**

My body, ravaged by disease and the long-term side effects of prescription drugs and medical treatments, has deteriorated to the level where it now determines what, when and where I can go and do. For example it is too difficult to stay away from home overnight. I must carefully and cautiously plan when to leave home during the day. Walking is painful and after minimal exercise I become breathless.

**Loss of ability to engage in activities which give my life joy and meaning:**

My physical condition has deteriorated to the extent that I'm unable to enjoy activities that have always been important to my sense of self and personal wellbeing. My life has become relentlessly constrained. My world is now very small.

Participation in activities outside my home are now limited to pleasures (!) like driving to the hospital, blood clinic or supermarket, attending a (very) occasional movie, and sometimes meeting friends for coffee or lunch. Susceptibility to infection means I have to be cautious about mixing in crowds.

These days I have to 'pace' myself, as it is too easy to overtax my body and my mind. Whenever I've done a little too much, the tiredness I experience is profound, I feel weary, exhausted, unlike anything I've ever felt.

Despite the constraints however, each day is a gift.

### **Loss of personal autonomy**

Self-determination, the right to make a personal choice or decision are guiding principles that have stood me in good stead throughout my life.

I've always respected the right of others to make their choices and decisions. I'd like to believe others would do the same for me -- respecting my right to know what is best for me.

Being able to choose the manner and time of my death, if necessary, is consistent with my personal values.

I do not wish to live a life without quality and dignity. I do not want to be diapered.

## **2. The effectiveness of services and support available to those who desire to end their own lives**

The time is fast approaching when the hospital cannot, due to the unavailability of legal PAD, provide me with relief from physical, psychological and existential pain and a compassionate and peaceful death.

Having said that, I gratefully acknowledge the NZ health system. Waikato DHB, and more specifically, the hospital's haematology department have, for the last seven years, provided me with exemplary specialist treatment, care and support.

Hospice services for people like me who have advanced, progressive end-stage disease assist one to live independently as long as possible, and I am grateful for the expertise, care and support given me by medical staff, especially the nurses and volunteers.

My choice for the remainder of my life, under current legislation, is a slow or prolonged death by palliative or terminal sedation. The other legal option, (if I can summon up courage) is suicide, a sad and solitary method, leading to an uncertain, possibly violent death by my own hand.

The claim that all pain can be successfully controlled is I believe incorrect. I expect that pain at the end of my life will not be able to be controlled. I have already experienced this pain.

I understand that loss of bowel and bladder function cannot be palliated. Likewise there is no palliation of psychological and existential suffering.

As I prepare this submission, I feel tired, indescribably tired, of living in a body that cannot and does not function well. I would like to be able to choose an alternative. Current law does not allow me to do this.

## **3. The attitude of New Zealanders towards the ending of one's life and the current legal situation**

Recent polling of NZ adults show 65%-75% support for legalised assisted dying, in conjunction with appropriate safeguards to avoid abuse. This means that 7 out of every 10 people consistently support law change.

As can be seen, the majority of voters in this country have for some years provided Parliament, our 'House of Representatives', with a consistent message to reform the current law to allow PAD for those who choose it.

This was the clear finding of Justice Collins in the Lecretia Seales case, that only Parliament can change the law.

The present Advance Directive (aka Advance Care Plans and Living Wills) allows for medical treatment to be accepted or refused. An 'End of Life Directive' would allow a patient to choose PAD, once agreed conditions have been met, even when the patient is no longer mentally competent.

Palliative care, Hospice and PAD should be regarded as complementary.

#### **4. International experience**

In international jurisdictions such as Netherlands, Belgium and Oregon, where such laws are long-established, there is no evidence of any systemic abuse occurring.

New Zealand has often led the world in terms of social reform. This is our opportunity to continue that tradition.

#### **Conclusion**

Now 72, I've had a good life. I've experienced the fulfilment of motherhood and the joy of grandchildren. Two successful professional careers have brought me tremendous satisfaction and sense of achievement.

Additionally, over the last 25 years, I have enjoyed carrying out a range of Judicial and Ministerial Justice of the Peace duties, and until very recently I regularly officiated at Marriages and Civil Unions. Sustaining me is the knowledge that together we can/will bring about an even more inclusive, intelligent, caring and democratic New Zealand.

To this end, I have one remaining project, to do everything in my power to bring about a change to the law regarding our care at End-of-Life.

**Any such law change will be too late for me, but with your help, future generations will benefit.**

**There is a vocal minority who strongly hold opposing views. They are fully entitled to have those views, and to live by them.**

**I do not seek to change their views, but they are not entitled to impose their beliefs on me.**

**The manner of my death should be my choice.**

*The sources I've consulted include the Voluntary Euthanasia Society New Zealand (VESNZ) End of Life Options Bill. I have also read widely and listened carefully to arguments for and against voluntary Physician Assisted Dying, in online forums and panel discussions.*



**WAIKATO &  
TARANAKI  
ANGLICANS**