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SUBMISSION BY THE VOLUNTARY EUTHANASIA SOCIETY NZ (END-OF-LIFE CHOICE) TO THE HEALTH SELECT COMMITTEE NZ PARLIAMENT ON PHYSICIAN ASSISTED DYING

This general submission is made on behalf of the Voluntary Euthanasia Society NZ Inc (End-of-Life Choice).

Date submitted: 2 Sept 2015

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We are authorised to present this submission on behalf of the Voluntary Euthanasia Society NZ (VESNZ).

VESNZ details:

Our Society has 1360 members at the moment, is a Not for Profit Organisation, and is governed by a National Committee elected yearly. In addition we have Branches and focus groups spread across NZ who work with the National Committee and their local communities

The aims and objects of VESNZ as in our Rules are:

(i) To change the law to entitle adults, with a terminal illness or an irreversible condition that makes their life unbearable, to have the right to choose how and when to die and to have medical assistance to accomplish that.

(ii) To provide information about and the opportunities for open and frank discussion on, the legal rights of people to obtain assistance in ending their lives and the legal alternatives that are available to such an action, when they suffer from, or may in the future suffer from, an incurable disease or condition which they find unbearable.

(iii) To provide all the assistance, sympathy and support that may legally be given in any aspects of assisted dying to persons faced with the prospect of suffering from an incurable disease or condition, which makes, or may in the future make, their lives unbearable and to give the same assistance, sympathy and support to their relatives, friends and helpers.

(iv) To provide venues and opportunities for debate and discussion on all aspects of the legal rights of people to obtain assistance to end their lives, and the alternatives to that, when a person is faced with an incurable and unbearable disease or condition.

It is important to note that VESNZ has always scrupulously acted within the law and considers that to do otherwise would compromise attempts to achieve legislative change.

Education – besides direct advocacy, our main role is educating both our own members and the public about the issues involved in PAD. This includes:

- Regular meetings with many groups, providing speakers including from overseas, with discussion of the issues across NZ
- Spreading documents from across the world and locally
- Publishing articles and views in academic journals
- Educating the media and politicians
- Providing a 3 monthly Newsletter to our members and others who desire it which outlines progress in the many spheres around the world and in NZ
- Providing a WEB site which includes resources and general information about the issues
- We are also on Twitter and Facebook
- We are frequently called upon to counsel individuals in health troubles and advise them of their lawful rights and options.

Advanced Directives – we have published a document called 'Guide to Dying – your Way' which is sold to many people across NZ and has become very popular. It is basically an instructional document on how to write an Advance Directive, the issues and complexities involved, and gives a template for individuals to use.

Overseas interactions - VESNZ is a member of the World Federation of Right to Die Associations which contains various organisations from around the world. Our National Secretary, Carole Sweney is also Secretary of the World Federation of Right to Die Societies.

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INTRODUCTION

The term 'Physician Assisted Dying' (PAD) is used in this submission. It is where at the request of a mentally competent person, a medical practitioner actively hastens death, by either providing the means where the patient can take the drugs causing death themselves, or directly administering the drugs by injection. (PAD is the same as Medically Assisted Dying).

The Voluntary Euthanasia Society NZ (VES) strongly supports 3 parts to PAD which will allow complete legislation thereby meeting the needs of all situations at end of life.

1. use in terminally ill patients e.g. cancer patients
2. use in individuals with grievous unbearable irreversible suffering which is relentless but may not cause death within 6 months e.g. motor neurone disease, very severe respiratory disease, and a number of other neurological conditions
3. provision for an End-of-Life Directive, written while mentally competent, but allowing PAD when the patient has become mentally incompetent

To simply have a law allowing PAD only in imminent terminal conditions, as has been suggested by some, would be inadequate. Some conditions such as in motor neurone disease are intolerable to the patient. It is noteworthy that this sort of slowly, but relentlessly, deteriorating neurological disease formed the basis of the Canada Supreme Court Case in February 2015[2]. Also, to have no provision for an End-of-life Directive would also remove the autonomy of many patients realising their worst fears after they have become incompetent. All three of the above provisions are allowed for in the Netherlands, Belgium, Luxembourg and the Quebec legislation and practices. USA states have provision for only self-administration of drugs in terminal illness and their laws are deficient in this respect, cutting out situations where the administration of PAD could otherwise be deemed appropriate.

'END OF LIFE OPTIONS BILL'. See Appendix 1 for complete document

An example of prospective legislation in New Zealand, consistent with several other jurisdictions where PAD was legalised was the Maryan Street End of Life Choice Bill (2013). We have modified this in some selected parts to an **'End of Life Options Bill'.**

Modifications include:

1) Section 6(1) A qualifying person may receive physician assistance to end his or her life if he or she-

(a) is mentally competent

(b) suffers from either of the following conditions:

(i) '***a terminal disease or other medical condition that is likely to end his/her life within 6 months'***. This is a change from 12 months to 6 months and is more consistent with other legislation.

(ii) '***constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable'***. These words are changed to those identical to the corresponding part in the Quebec Legislation.

2) ensuring that the second practitioner is **independent** and that the Health Ministry creates a formal body called **'Support and Consultation on End-of-Life NZ' (SCENZ).** This will be an experienced group of participating medical practitioners who will be responsible among other things, for setting standards, guidelines, and providing the independent medical practitioner. This change is based on a model used by the Netherlands. (See clause 40 of Bill).

3) a change which includes ensuring that a medical practitioner must be present whether the patient is self- administering the drug or the medical practitioner is directly administering the drug. He/she must bring the drug to the patient, and if not used must take it away and place in safe custody (see clause 22(5) of Bill).

Otherwise the End of Life Options Bill is fundamentally the same as the Maryan Street End of Life Choice Bill (2013) which has previously been in the Parliamentary Ballot.

SUMMARY OF SUGGESTED 'END OF LIFE OPTIONS BILL'.

The suggested Bill requires a voluntary request made by a mentally competent person i.e. knowing exactly what they are asking and fully informed of alternatives. Individuals may seek medical assistance to die, under carefully defined circumstances. He or she (18 years or over) must suffer from either:

a) a terminal illness or other medical condition likely to end his/her life within 6 months.

b) constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

Safeguards include:

The individual must request assistance in writing twice, with at least a 7 day interval, from a medical practitioner who will certify:

a) the qualifying conditions above exist

b) there has been no coercion from family or others

c) the patient is mentally competent

d) he/she has given advice to the patient on treatment options including palliative care

e) he/she has given advice to the patient to talk to family and seek counselling

In addition a second independent medical practitioner must interview the patient, read the first medical practitioners findings and record their opinion on an official form. If they agree with the first certifying medical practitioner, the procedure may take place. This independent second medical practitioner will be drawn from a panel of experienced participating medical practitioners set up by the Health Ministry (Support and Consultation on End-of-Life in NZ – SCENZ panel).

The Bill also allows mentally competent people to write a legally witnessed "End of Life Directive", which will allow them to qualify for assistance to die in the future should they develop one of the conditions as for a competent person above, but have become incompetent to understand the issues and make a valid decision. These Directives are lodged with a Registrar, and there are further conditions around them including regular renewal if the individual is still mentally competent. It provides provision for an Advocate to show the patient's End of Life Directive to a certifying medical practitioner, and represent their interests. For instance if a patient has become demented after making the End of Life Directive, they may have already requested assistance to die if they develop terminal cancer or severe neurological disease (see Appendix 2 for an example of such a Directive). The procedures when considering the End of Life Directive are very similar to that for a competent patient, and a certifying and second independent medical practitioner are still required while considering PAD.

The Bill allows for oral self-administration of a prescribed drug or administration of an injected drug by a medical practitioner. The medical practitioner is required to be present whenever PAD is administered even if the patient is taking the drug themselves, to prevent complications and ensure care of the drug should use be delayed.

It is important to realise that discussions with the patient will be considered and usually lengthy, and that even if the patient wants PAD it will not always be considered appropriate. Also, once a decision is taken to provide PAD, the time when it happens may be weeks or even months away e.g. in conditions where the time of death is not foreseeable.

Detailed documentation on proscribed forms is sent by the medical practitioners involved to a central Registrar (probably within the Ministry of Health) who will report to a Government appointed Review Committee, who will in turn report to Parliament annually.

ETHICAL AND RELATED ISSUES

Many of our ethical positions in New Zealand are common to religious and non-religious because they are derived from our Judeo-Christian heritage. Because many supporters of PAD are religious, and also some of the more vigorous opponents come from religious groups on the fundamentalist right, a section at the end of this paper discusses some specific Christian concepts which may not be relevant to others. Also we provide a short summary of the human rights issues as they relate to PAD from the Canada Supreme Court (Carter v Canada 2015) judgements[2].

1. SANCTITY OF LIFE

In the western world of medicine, this important concept seems to be derived from:

a) the biblical commandment – "Thou shalt not kill" (10 Commandments). The proper translation from both Hebrew and Greek is 'Thou shalt not murder'.

b) the classical Hippocratic Oath, which says 'I will neither give a deadly drug to anybody who asked for it, nor will I make any suggestion to that effect'. This has been widely replaced by more modern oaths which usually do not mention the Hippocratic Oath[1]. For instance the oath taken by Auckland School of Medicine graduates states: *" I solemnly promise to practise the art of Medicine with due care and with conduct becoming a physician. In the exercise of my profession I will ever have in mind the care of the sick and the well being of the healthy. In the furtherance of these ends I will use my knowledge and will strive to perfect my judgement. I will furthermore, keep silence on any matters I may witness or hear in the course of my professional work, which it would be improper for me to divulge. I promise, as a graduate in medicine, that I will promote the welfare and maintain the reputation of the medical profession. I also accept my responsibility to pass on the knowledge I have gained and recognise my debt to my preceptors".*

Sanctity of life is clearly not an absolute rule in our society:

(i) In the Bible, the commandment "do not kill' was followed by a raft of other commandments which prescribed death for certain situations e.g. Exodus 21:15-17.

(ii) NZ currently condones killing someone in self defence (e.g. police do this and an ordinary citizen may be able to justify it), where the greater good will result (e.g. police shooting a dangerous individual to protect others), and in a just war.

(iii) Therapeutic termination of pregnancy is allowed in NZ law to protect the mother's life or to prevent the birth of a child with major defects.

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[1] Orr R, Pang N, Pellegrino E et al. Use of the Hippocratic Oath: a review of the twentieth-century practice and a content analysis of oaths administered at medical schools in the USA and Canada in 1993. The Journal of Clinical Ethics 8, 1997 (Winter): 377-388

(v) In clinical medicine there are many situations where the action of the medical practitioner will result in an earlier death than otherwise would have occurred, including refusal of therapy, withdrawal of therapy, and terminal sedation in palliative care with withdrawal of food and fluids.

While the sanctity of life is easily shown not to be an absolute, it is obviously important, and the basic ethical assumption 'in favour of life' is a central tenet of our civilisation. So what is the issue which really matters here? For the individual, life is precious only when it is worthwhile. In some cases, the individual will find the release of death to be more important than hanging on to a miserable existence of unbearable suffering, or stretching out the end in a terminal disease. In other words the harm caused by death is to the individual who loses some time in life; but, for some individuals, death which brings an end to suffering is not harm, but a benefit.

Prolonging the time to death: in a strange twist to the arguments for and against PAD, the absence of a lawful solution allowing assistance to die may actually shorten life. Sometimes the individual knows that they are weakening as the end approaches, and they commit suicide while they still have the strength. They would have lived longer if they could have been sure that a medical practitioner would help them die when they were unable to do the physical act themselves. We have such cases in NZ on a regular basis. This was also one of the main issues debated in the recent Supreme Court Judgement in Canada.[2]

2. THE DIFFERENCE BETWEEN PAD AND WITHDRAWAL OF LIFE SAVING THERAPY

Medical practitioners have long held the principle that 'passive euthanasia' (withdrawal of support allowing death), is very different from active PAD. It is claimed that there is a 'bright line' between the two types of actions. In many instances this may be true e.g. withholding antibiotics in a patient with severe Alzheimer's disease may or may not hasten death in the long run. But in intensive care situations, where life support is being withdrawn because further treatment is considered futile and harmful, the 'bright line' of difference often disappears. The effects are far more dramatic.

Some examples of this include:

(i) withdrawal of inotropes (blood pressure supporting drugs) where life is dependent on them.

[2] Supreme Court of Canada Citation: Carter v Canada (Attorney General) 2015 SCC 5 Date 6 Feb 2015

(ii) withdrawal of a respirator in a patient with muscular dystrophy who has been unwisely resuscitated when they have reached end stage muscular weakness making them unable to breathe.

(iii) extubation of a patient with an untreatable large head and neck cancer who has been resuscitated before the absence of a potential for treatment could be assessed. Immediately on withdrawal of the tube, suffocation will occur.

(iv) withdrawal of respiratory support in massively brain damaged patient e.g. head injury or cerebral bleed

(v) withdrawal of extra corporeal bypass support in a patient who is dependent on it for life but for whom the treatment has been judged to be futile

In such cases as the above, the intensive care physician discusses the option with family, and/or patient if conscious, and they together agree that it is in the best interests of the patient that forgoing treatment should take place. The medical professionals regard themselves as having exhausted all beneficial therapy, and reached the stage of causing harm by persisting with life support. The action which they take will definitely cause a hastened death in the patient. In June 2012 an exhaustive report of a case in the Supreme Court of British Columbia looked at these issues [3] According to a group of expert witnesses who were ethicists, the differences between the withdrawal of therapy such as in the above cases and physician-assisted suicide or voluntary euthanasia in end stage illness is ethically insignificant. This was also agreed by some ethicists who were opposed to PAD for other reasons.

The Supreme Court of Canada (February 2015), after an appeal involving the case above, stipulated: '*it was agreed that the current unregulated end-of-life practices in Canada – such as the administration of palliative sedation and the withdrawing or withholding of life saving or life sustaining medical treatment – can have the effect of hastening death and that there is a strong social consensus that these practices are ethically acceptable. After considering the evidence of physicians and ethicists, it was found that the 'preponderance' of the evidence from ethicists is that there is no ethical distinction between PAD and other end-of-life practices whose outcome is highly likely to be death'.* [2]

[3] Carter v Canada (Attorney General). In the Supreme Court of British Columbia. June 2012. Registry Vancouver.

3. THE DIFFERENCE BETWEEN "KILLING" AND PAD

Many opponents of PAD seem unable to see the vast ethical difference between murder and PAD. As seen below they are quite different ethically:

'KILLING' - when a wilful violent unwanted killing occurs it is called murder and, over and beyond the law, many ethical principles are broken including harm to the person, breaching the victim's autonomy, lack of compassion and justice.

'PAD' - in comparison, the process in the End-Of- Life Choice Bill is that an adult competent person, makes a written request to a medical practitioner to assess him/her and assist him/her to die. There are many safeguards including the skill of at least two medical practitioners, the provision for at least two written requests, assessment of competence, the avoidance of coercion, a waiting time before a request is acted upon, and reporting of all cases to a Registrar, who reports to a Review Body, which in turn reports to Parliament.

From an ethical point of view, the act of assistance under the carefully prescribed conditions, can be considered as beneficial to the patient, a compassionate act, and respectful of their autonomy, usually allowing them to say a conscious farewell to their family and friends. It may be regarded as an extension of the treatment given by the medical practitioner to relieve the patient suffering. Furthermore the safeguards as proposed are such that the participating health professionals and others are protected. There is one thing needed to complete the ethicality – a change of NZ law.

4. THE DIFFERENCE BETWEEN 'IRRATIONAL SUICIDE' AND PAD

The use of the word suicide also causes much confusion and is best avoided in the context of PAD.

'SUICIDE' - irrational suicide is impulsive, often violent, and causes extreme distress to family and friends. Almost always the mental condition which leads to the act is treatable and hence reversible. This type of suicide is of great concern, but opponents of PAD purposely continually pretend that it is the same as PAD.

PAD -the term Physician Assisted 'Suicide' is a type of PAD where at the request of the patient, the physician prescribes the drug, and the patient takes it to end their life (the only type of PAD available under USA jurisdictions). This could be called 'rational suicide' and it is usually hastening death when death is fast approaching anyway, but the term 'suicide' is probably best avoided. Again this type of PAD is beneficial to the patient, prevents suffering, is a compassionate act from the

doctor, is respectful of the patient's autonomy, and allows the relatives and friends to say goodbye before the ravages of disease and intense sedation make this impossible. It also allows some ceremony and spiritual and religious involvement. Knowing that this option is available to them also gives the patient peace of mind even if eventually they do not use it, and may promote prolongation of life.

Irrational suicide is completely different to PAD

5. AUTONOMY OF PATIENT

Over recent years autonomy of the patient has been increasingly recognised as an important ethical principle.[4] As in all advanced countries, in NZ a patient is at liberty to refuse any treatment offered even if it is life maintaining.[5] Written consent must be gained for invasive interventions. An individual may now write an Advanced Care document which prescribes how they should be treated should they become incompetent, and this stands as a legal document.[6]

However, an individual can live a full self determining life making medical decisions along with their carers, but when it comes to dying (in New Zealand), they are not allowed to make a decision to determine the manner of their dying, short of committing suicide in isolation. This situation smacks of paternalism and probably a degree of professional capture. 'We are the expert doctors and nurses – listen to us and we will give you an easy death'. If the patient says 'I would prefer you to help me die a little earlier so that I don't have to lose my dignity, become semi-conscious, suffer in various ways, and become totally dependent on others', some physicians say to them 'that is not possible and we oppose assisting you to die'. Physicians are required to respect patient autonomy, to act in their patients' best interests and not to abandon them. The personal values of the physician are respected but must not take precedence over those of the patient.

There is also evidence to suggest that the possibility of assisted death, if continued life becomes unbearable, may in itself alleviate suffering, even if the patient does not in the end take that course. The evidence coming out of Oregon State (USA) show that some patients who get a lethal prescription do not use it. Certainly some possibly die before they can use it, some may end up in a

[4] Beuchamp T, Childress J. Principles of biomedical ethics. Sixth ed. Oxford, New York: Oxford University Press, 2009

[5] Ministry of Justice. New Zealand Bill of Rights Act. In: Ministry of Justice, Editor. Wellington: NZ Government 1990

[6] Health and Disability Commissioner. Code of Health and Disability Services Consumers' Rights, In: Health and Disability Commissioner, Editor. Wellington, Auckland: NZ Government 2009

place where they can no longer access it (some hospitals), but some get 'peace of mind' from having it close by and so get on with living.[7] It is often stated by patients that 'being in control of the process' gives them significant peace of mind, and the ability to make the most of the time they have left.

5. THE "SLIPPERY SLOPE".

One of the fears of those in opposition to Voluntary Euthanasia law is that it will create a 'slippery slope'. There are 2 components to this:

i) that because such a law is passed, there will be movement of society ethical norms in the future to allow different groups to be targeted.

Ethical norms are always evolving in society. Some instances include: slavery is now regarded as unethical where it was previously accepted in many countries; ethics around gender equality have changed; therapeutic termination of pregnancy under prescribed situations is now considered ethical by the majority; same sex couples are now allowed to get married. Future generations will have to make these decisions for themselves. An example of this, is that the Belgium Parliament, with the same 80% majority as for the initial euthanasia law, and strongly supported by the people, has extended the possibility of assisted death to mentally competent minors. Such decisions are made as part of the normal democratic process.

ii) that the vulnerable will be at risk of being assisted to die against their will

In a study from both the Netherlands (20 year study) and Oregon (since 1998), there is clear evidence that the vulnerable are not at an increased risk of being assisted to die against their will.[8] Data was taken from nationally required reports, independent studies and specialised studies. Rates of assisted dying showed no evidence of heightened risk to the elderly, women, uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations.

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[7] Oregon Public Health Division. Characteristics of end-of-life care of 525 DWDA patients who died after ingesting a lethal dose of medication as of January , 2011, by year, Oregon, 1998-2010, 2011.

[8] Battin P, van der Heide A, Ganzini L et al. legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in 'vulnerable' groups. J Med Ethics 2007; 33: 591-597

In the Quebec Select Committee report on 'Dying with Dignity', to the National Assembly of Quebec (2012)[9], the Committee studied this matter and others over 2 years and physically visited and reviewed various jurisdictions where PAD is legal. They reported that support in the Netherlands showed 85% of people in favour of their law (5% against and 10% undecided). The Royal Dutch Medical Association said that the quality of death had improved, palliative care had improved substantially, PAD was only contemplated as a last resort, the public's trust in doctors is high and growing, and the slippery slope had not materialised i.e. PAD has not increased among people over 80, the disabled, the chronically ill, the economically disadvantaged or other groups included in this argument. The Canadian Supreme Court (Feb 2015), while considering the body of evidence from jurisdictions allowing legalised PAD, concluded that these regimes have produced a body of evidence about the practical and legal workings of PAD and the efficacy of safeguards for the vulnerable. They stated that '*although none of the systems have achieved perfection, empirical researchers who have experience in those systems are of the view that they work well in protecting patients from abuse while allowing competent patients to choose the timing of their* deaths.'

The Court also stated that '*physicians are capable of reliably assessing patient competence, including in the context of life and death decisions. It is possible to detect coercion, undue influence, and ambivalence as part of the assessment process'*.[2]

After an exhaustive review of the evidence the Supreme Court agreed that there was no reason or evidence to suspect that the slippery slope and descent into homicide will occur.[3]

Some particular concerns by opponents of PAD include:

(a) Depression: an often debated issue is whether severely depressed patients will choose voluntary euthanasia, purely because they are depressed. The unbearable suffering condition must be 'irreversible' as stated in the law of all legalised jurisdictions. Most depression is reversible with appropriate care. If a patient is extremely depressed they will have disordered thinking (be mentally incompetent) and would not fit the criteria for assistance. Also, the medical practitioners, if not a psychiatrist themselves, always have the option to refer the patient to a psychiatrist if there is any doubt, and as seen above, it is not a problem where studied. From time to time, a refractory depression under long term psychiatric care with no resolution over many years could possibly be judged to fit the criteria for PAD, as this can be undoubtedly be equally devastating as the worst

[9] Quebec Select Committee report "Dying with Dignity" to the National Assembly of Quebec March 2012 (on internet)

physical medical conditions. These are the small numbers of cases which have received PAD in Belgium and the Netherlands.

(b) Disabled: opponents to voluntary euthanasia envisage society using it as an excuse to get rid of the disabled. This is not true as shown by the studies on vulnerable people above. Furthermore, if the patient is mentally disabled with disordered thinking, they are excluded from PAD, because the patient has to be mentally competent. If the patient is physically disabled they should not be deprived of the same degree of autonomy as others, and should not be presumed to be less likely to be mentally competent and more likely to be susceptible to coercion or undue influence. Discrimination against the disabled is common but this should not be conflated with PAD. For instance the inability of a disabled person with terminal cancer to have PAD, would merely be another form of discrimination, if able bodied people have that option.

(c) Encouraging irrational suicide, particularly in the young: there is no evidence to support this. For instance, the Netherlands suicide rates are slightly lower than New Zealand after 20 years of legalised PAD (10/100,000 compared with New Zealand 10.1/100,000). Suicide rates in Switzerland and Luxembourg are decreasing. In Oregon the suicide rate remains high as previous to the PAD legislation, along with most other USA states, but no higher than some other states without legalisation of PAD. Irrational suicide has multifactorial origins and to state that there is a causation factor from PAD is simply not supported by the facts.

(d) Elderly abuse and 'being a burden on others': the requirements of legislation such as the suggested 'EOL Options Bill' makes abuse of the elderly in the context of PAD virtually impossible.

An argument often used by opponents to PAD is that especially the elderly will choose PAD to end their lives because they don't want to be a burden on others. It should be stated that this is a legitimate and common feeling among many people. It is not wrong to feel that way and many parents have sacrificed parts of their ambitions in life for the sake of their children, as have children for their parents on occasions. However, PAD is not possible for them unless they meet the strict criteria and safeguards required. The elderly do not qualify for PAD by being lonely, depressed, feeling as though they are being a burden to others, or have 'completed their life' and do not want to live any longer. So just because an elderly person feels that way, doesn't mean that PAD will be available to them. Nasty relatives are usually operating 'under the radar', but if a

mentally competent elderly person applies for PAD and comes under the scrutiny of 2 doctors trained to look for coercion, it is hard to see how this sort of abuse could happen.
It is important for the elderly to feel wanted, cared for, and are looked after, and this happens to a large extent in NZ society, even though elder abuse is far too common. But there is absolutely no evidence that it occurs in the context of PAD.

(e) Legalisation of PAD impedes the development of palliative care: experience throughout legalised jurisdictions has confirmed the opposite. Also, in Belgium for instance, palliative care and PAD have developed synergistically. [10] [11]

(f) People being 'euthanised' without their consent: opponents have made much of a report from Belgium in 2010[12] which was interpreted to mean that a non-eligible number of patients were being assisted to die without their consent, but this was a mis-interpretation. The same authors have revisited the data. It is shown that the vast majority of the 66 reported 'life-ending acts without explicit consent' were in fact mislabelled by the critics as 'non-voluntary life-ending' and rather represent compassionate attempted shortening of the dying process: the purpose of the acts was symptom control, the drugs used were the same as for deep sedation and quite different from those used for euthanasia, the patient had often become incompetent, whilst having previously requested PAD, and the physicians themselves did not label them as life ending acts.[13] [14]. In fact so called 'life-ending cases without explicit consent' probably happen in a lower percentage than in New Zealand[18,19], and are at least scrutinised!

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[10] Chambaere K, Bernheim J. Does legal physician-assisted dying impede development of palliative care? J Med Ethics 2015; 0:1–4.

[11] Bernheim, J. L., Deschepper, R., Distelmans, W., Mullie, A., Bilsen, J., &Deliens, L. (2008). Development of palliative care and legalisation of physician-assisted dying: antagonism or synergy? *British Medical Journal, 336*, 864–867.

[12] Chambaere K, Bilsen J, Cohen J et al. Physiaican Assisted deaths under the euthanasia law in Belgium: a population based study. CMAJ.2010 June 15; 182(9): 895-901.

[13] Chambaere K, Bernheim JL, Downar J, Deliens L. Characteristics of Belgian 'life-ending acts without explicit patient request': a large-scale death certificate survey revisited. Canadian Medical Association Journal Open: E262-E267. Published online Dec 2, 2014

[14] Chambaere K, Stichele RV, Mortier F, Cohen J, Deliens L. Recent Trends in Euthanasia and other End-of-Life Practices in Belgium. N Eng J Med March 19, 2015; 372:12

Hypothetical harm to hypothetical people: it could be considered unethical to refuse to relieve the suffering of an actual patient who requests and requires such relief, simply in order to protect other hypothetical patients from hypothetical harm.

6. PALLIATIVE AND HOSPICE CARE

Development of palliative care and hospices in most of NZ has been admirable. It is fundamentally important to know that the Voluntary Euthanasia Society NZ wholeheartedly endorses these modes of treatment and would see most patients described in the intended Bill as being helped by these services. In Oregon most patients who have assisted death have been treated in a hospice environment. In the Netherlands and Belgium, palliative care doctors have been some of the leaders in the voluntary euthanasia movement.[11,15]

However, there are a number of issues which should be considered:

i) it is clear that palliative care cannot always relieve physical suffering or 'existential suffering' due to loss of autonomy and dignity, and there are a number of patients who ask for assisted medical death in spite of good palliative care. Palliative care health professionals argue that their techniques are becoming increasingly refined, but some patients find the prospect of dying while under sedation repugnant and an affront to their dignity. They would prefer not to 'be cuddled to death'. Some attach great value to the emotional and spiritual experience of leaving life ceremoniously and in the embrace of their loved ones.

ii) terminal sedation (palliative sedation, continuous deep sedation) refers to the situation where a patient (generally terminally ill and very close to death) is sedated to the point of deep unconsciousness until death. It is used for relief/management of refractory and unendurable symptoms (breathlessness, suffocation, nausea and vomiting, agitation, fitting, pain and restlessness). The patient will either die of their underlying disease, or dehydration. Artificial administration of food and fluid is usually considered as a futile treatment and withdrawn at the same time sedation is started. The literature describes percentages of terminal sedation varying up

[15] Berghe PV, Mulie A, Desmet M, Huysmans G. Assisted dying- the current situation in Flanders; euthanasia embedded in palliative care. European J of Palliative Care 2013 20(6), 266-272

to 12% of all deaths.[16] It is understood that staff give drugs to relieve suffering and any 'double effect' which may hasten death is incidental. However, it is clear that the patient will die shortly, and the situation has little difference from medically assisted death which hastens the patient's demise, especially when a patient is deeply sedated for a few days without hydration. There seems to be a 'cognitive dissonance' in the thinking of staff where they are trying to hold the principle of sanctity of life along with the relief of suffering. Objectively, it could be regarded as a form of prolonged euthanasia. Not only that, it is often done with family permission rather than the patient's, because the latter has reached the stage where they cannot think properly. This could be argued to be less ethical than if PAD is decided upon and carried out while the patient is still competent.

The above is not an argument against terminal sedation which is desirable in certain instances, and is an important tenet of palliative care everywhere, especially where the patient chooses not to use a PAD option. But health professionals administering terminal sedation are in a poor intellectual position when arguing against PAD.

iii) Finally, palliative care and PAD are not mutually exclusive; the former should be universally provided at a high level, and the latter should be available as an adjunct where requested [11, 15].

7. RELATIONSHIP BETWEEN DOCTOR AND PATIENT

A frequently used argument against voluntary euthanasia is that the physician – patient relationship will be destroyed. Opponents seem to envisage that patients will be very suspicious of their doctor who 'may kill them without asking'. Considering the safeguards around all PAD legislation of this type where written requests must be made etc, probably the opposite is true. The physician-patient relationship may be enhanced by knowing that the physician will not abandon him/her at this particularly moving and intense period of life (an ethical principle of 'non-abandonment'). In 2008, the GFK Group, a market research organisation, reported that 88% of respondents in Belgium and 91% in the Netherlands trust their doctors – one of the highest rankings in Europe[17]. In addition under the section on "slippery slope" above, the approval level of 85% in the Netherlands is consistent with trust in health professionals.

[16] Onwuteaka-Philepsen BD, Brinkman-Stoppelenburg A, Penning C et al. Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990-2010: a repeated cross-sectional survey. The Lancet 2012 (published online July 11)

[17] Gfk Trust Index, Gfk Custom Research August 8th 2008.

Also, it should not be assumed that physicians and other health care providers will discard their focus on assisting patients and preserving life simply because assisted death becomes a legal option in limited circumstances.

8. LAW

It is an important societal and ethical principle that health professionals should act lawfully at all times. The present situation that criminalises PAD in certain qualified situations, and as a last resort, is highly undesirable. The NZ Criminal Law on homicide and abetting suicide does not distinguish between PAD and murder, or PAD and irrational suicide, and in this respect is overbroad and has disproportionate effects. This was also a major part of the unanimous Canadian Supreme Court conclusions.[2]

Many people are aware of personally related instances, where doctors, nurses, and family have hastened death at the end of life, by increasing the drugs with the intent to curtail suffering or hasten death. There are now regular, well publicised court cases in NZ where family have acted unilaterally because their relative could not endure the patient suffering further. The uniform motivation is that the patient, and often the family, have suffered enough and they regard their act as a compassionate one. They are also acting at the begging of their loved one, mostly a parent. It has become clear that a significant group of doctors and nurses now act unlawfully during end of life care. It has been shown in scientific studies of General Practitioners in NZ, that illegal and unreported hastening of death regularly takes place in NZ.[18],[19] This is done in spite of significant risk or prosecution to the health professional.

A quote by Dworkin puts the situation succinctly: "The law produces the apparently irrational result that people can choose to die lingering deaths by refusing to eat, by refusing treatment that keeps them alive, or by being disconnected from respirators and suffocating, but they cannot choose a quick, painless death that their doctors could easily provide".[20]

[18] Mitchell K, Owens G. End of life decision-making in New Zealand general practitioners: a national survey. NZ Med J 2004; v117 no 1196 (published on line 18th June 2004)
[19] Malpas P, Mitchell K, Koschwanez H. End-of-Life medical decision making in general practice in New Zealand – 13 years on. NZMJ 24 July 2015, Vol 128 No 1418 pg 27-39
[20] R Dworkin. Life's dominion: an argument about abortion and euthanasia. 1995 Harper Collins. Page 184

9. DEMENTIA

Dementia raises a difficult issue, but it needs adequate consideration. To many individuals, their worst fear is ending their lives with severe dementia. Many beds in specialised rest homes are filled with patients who cannot recognise their relatives, and are totally physically dependent (incontinent, sometimes curled up in bed or restrained, and unable to feed themselves). They are being spoon or tube fed by a carer to try to keep their failing nutrition adequate, which merely increases their longevity, and they often live for many years to the dismay and sadness of relatives. This often leaves relatives and carers with horrible memories. With people living to an increased age, this situation will worsen.

At the moment a competent person can write an advanced directive, which can stipulate that should they reach a severe stage of dementia such as described above, that they should not be given fluids or food ie death by starvation. This may be relatively hard for a relative or advocate to insist upon, but it is entirely legal.

However, within the 'EOL Options Bill' there is the possibility that the End of Life Directive can be used to ask for PAD should severe dementia such as above be reached (see Appendix 2 for an example of such an End-of-Life Directive). The end points of not recognising family or friends combined with total physical dependence are easily established and PAD would usually occur after many months of such a state to be quite sure. However there remains the difficulty of hastening the death of a person who is not able to understand what they have requested when of sound mind. Some demented patients appear to be suffering, but others seem to enjoy the simplest things of physical life. This is an additional hurdle for a doctor to jump, although many are quite clear that that is what they would like for themselves in such a circumstance.

10. THE NEW ZEALAND MEDICAL ASSOCIATION (NZMA) VIEWS

The NZMA has taken a strong stance against PAD considering it unethical. However, the body does not represent all medical practitioners, and has not done a survey of practitioners on this subject. Furthermore its ethical stance does not correspond to the views of many ethicists from across the world and some other medical associations.[2]

A small study of general practitioners in the Waikato region in Dec 2014, suggested that approximately 47% of the responders would support/or probably support PAD providing adequate safeguards are in place[21]. A similar percentage was opposed. A recent poll in NZ Doctor (July 2015) has also reported that almost 12% of doctors, out of those who responded, had

[21] Havill J. Physician assisted dying – a survey of Waikato general practitioners. NZMJ. Feb 20 2015;128(1409):70-71

admitted to assisting a patient to die; 44.5% thought they should have some role in assisting terminally ill patients to die; and 45.5% believed that a law change was needed to allow the practice. Similar percentages were opposed, but the fact that there is roughly a 50/50 split in views means that the NZMA is not necessarily representing the views of many of their members and needs to have a wide consultation on the appropriateness of PAD.

In our view the NZMA ethical stance is rigid, does not take account of modern day medicine, and is outdated.

SOME CHRISTIAN/RELIGIOUS PERSPECTIVES

A. 'GOD GIVES AND HE TAKES AWAY'

Some Christians and Muslims argue that God gives us our life and hence we have no right to authorise anyone to hasten our death. This concept needs to be considered in the context of our normal lives where we have the autonomy to make many health decisions which causes our life to be either lengthened or shortened e.g. we may refuse medical treatment, or we may choose to undergo many treatments in the hope of prolonging our life. In general, Christians believe that God has given us free will which is part of being in His image. So we have extensive autonomy for life's decisions, but when we wish to hasten our dying to limit our suffering, some tell us we are not allowed to do that – 'God would prefer you to suffer rather than get help to end your life. God would prefer you to lose all your dignity rather than being able to say farewell to your loved ones while still conscious'. We are dying anyway, but to enable a peaceful death is against God's will? Is it? This does not seem compatible with our loving God, and sorrows will be no more when we depart this life to be with God.

B. SACRIFICE MAY BE GOOD FOR YOU

Some Christians may argue that pain and suffering are good for your character and this is quite a pervasive concept in Christian thought. There is no doubt that the Bible supports suffering for the sake of the spreading of the gospel, and the suffering of Jesus is seen as necessary for our salvation. Suffering can also bring out good qualities in people. However, it is difficult to find a place where God or biblical writers say that futile suffering and pain is to be desired as one approaches death. Furthermore some argue that those caring for the suffering grow spiritually – but again it is difficult to accept that my suffering should happen to ennoble those watching me suffer.

C. TRANSITION FROM LIFE TO DEATH

It can be argued that Christians who regard death as a transition from life to another better state should be less worried about 'hanging on to life at all costs' than others.

D. DO RELIGIOUS PEOPLE SUPPORT PAD?

It is important to realise that those Christians who argue so strongly against PAD are in a minority. They do not represent most Christians. Polls of the general population in NZ have repeatedly supported PAD with majorities of 60-70%. A 2014 survey showed that 82% of New Zealanders supported legalisation of PAD. In this survey, 41% of the extremely/very religious, and 81% of the

slightly/moderately religious, supported legalisation of PAD.[22] Both Australia and Britain have done polls to assess the views of religious groups. The Guardian[23] reported a poll in 2013 in Britain which showed that large majorities of believers are in favour of voluntary euthanasia (VE). The only groups who had majorities against VE were Muslims and Baptists! In Australia the Australia Institute[24] surveyed attitudes to VE with the question: "*thinking about VE, if a hopelessly ill patient, experiencing unrelievable suffering, with absolutely no chance of recovery asks for a lethal dose, should a doctor be allowed to provide a lethal dose"*. Nearly nine out of ten Anglicans, three out of four Catholics supported the above. In all other Christian groups combined, the majority supporting the proposition was lower but still 70%. Christians are active in supporting the legalisation of PAD in NZ and other countries.

[22] New Zealander's Attitudes toward Physician-Assisted Dying. Journal of Palliative Medicine v18,no2, 2015
[23] Andrew Brown The Guardian, Tuesday 30 April 2013
[24] The Australia Institute. Poll conducted by Newspoll 2012

HUMAN RIGHTS

Closely linked to ethics is a consideration of human rights. The Feb 2015 Canadian Supreme Court Judgement is ground breaking in this respect.[2] They stated that their Criminal Code unjustifiably infringes their Charter of Human Rights **'***and is of no force or effect to the extent that it prohibits PAD for a competent adult person who a) clearly consents to termination of life and b) has a grievous and irremediable medical condition (including an illness, disease, or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition'.*

They argued that life, liberty, security and equality are all impeded by a ban on PAD which is fundamentally unjust.

a) Life – the Court stated that *'the prohibition of PAD has the effect of forcing some individuals to take their own lives prematurely, for fear they will be incapable of doing so when they reached the point where suffering was intolerable'* i.e. it was judged that the prohibition of PAD deprives some individuals of life.

The Court '*did not agree that the existential formulation of the right to life requires an absolute prohibition on assistance in dying, or that individuals cannot 'waive' their right to life. That would create a 'duty to live' rather than a 'right to life', and would call into question the legality of any consent to the withdrawal or refusal of life saving or life sustaining treatment'.*

They said '*the sanctity of life is one of our most fundamental societal values, but human rights also encompasses life, liberty, and security of the person during the passage to death. It is for this reason that the sanctity of life is no longer seen to require that all human life be preserved at all costs. and it is for this reason that the law has come to recognize that, in certain circumstances, and individual's choice about the end of her/his life is entitled to respect'.*

b) Liberty and Security – '*prohibition of PAD limits the right to liberty and security of a person, by interfering with fundamentally important and personal medical decision making, imposing pain and psychological stress and depriving her/him of control over her/his bodily integrity.*

An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The law allows people in this situation to request palliative sedation, refuse artificial nutrition and hydration, or request the removal of life sustaining medical equipment, but denies them the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. It also impinges on their security.

c) Equality - it was found *'that the prohibition of PAD imposed a disproportionate burden on persons with physical disabilities, as only they are restricted to self-imposed starvation and dehydration to take their own lives. This distinction is discriminatory and not justified'*

The principles discussed above apply to our Criminal Code and NZ Bill of Rights, and New Zealand law is subject to the same criticisms. However, unlike Canada, in New Zealand, the Bill of Rights is 'subservient' to the rest of New Zealand law and cannot override the Criminal Code.

APPENDIX 1 End of Life Options Bill (this is a suggested Bill for discussion and is a revision of the previous End of Life Choice Bill (Maryan Street) which was in the Ballot Box in NZ Parliament and withdrawn in 2013)

OC 16605/6.0
Amended by VES July 2015

IN CONFIDENCE

End of Life Options Bill

Member's Bill

Explanatory note

General policy statement

The purpose of this Bill is to provide individuals with a choice to end their lives and to receive assistance from a medical practitioner to die under certain circumstances.

Those circumstances are:

- that the person making the request must be mentally competent, as attested by 2 medical practitioners:
- that the person suffers from a terminal illness which is likely to cause death within 6 months, or from constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.
- when implementing a registered End of Life Directive which is consistent with the circumstances above.

Any person making a request for physician (that is, medical practitioner) assisted death must be encouraged to consult with family or a close friend and to seek professional counselling during the course of making his or her request. They must be given a period of at least 7 days for reflection on the decision. The certifying medical practitioner must certify that the person has made a valid request to end his or her life, that he or she is mentally competent and has the condition specified in the request, and that he or she has been advised of all available options,

including palliative care. A second medical practitioner must certify similarly, after a separate examination of the applicant.

The Bill also provides for a person, while mentally competent, to draw up a registered End of Life Directive in which he or she specifies his or her wishes for physician assisted death in the event that he or she suffers from a terminal illness or constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable, and is not mentally competent otherwise to make a request for physician assisted death. Such End of Life Directives must be consistent with the provisions of this Bill and must be refreshed every 5 years and may be cancelled or varied at any time. One or more people may be appointed by the person registering an End of Life Directive as advocates for him or her if he or she becomes mentally incompetent. The role of the advocate so appointed will be to ensure compliance with the person's End of Life Directive.

The Bill provides for levels of protection against abuse or coercion. First, the person making such a request must be able to attest, to the satisfaction of a medical practitioner, that he or she has not been subjected to any coercion from any interested party, including family members. The person is also protected from having his or her express wishes made in accordance with this Bill altered or frustrated by another person. Secondly, no medical practitioner may be coerced or required to participate in the provisions of this Bill. Such medical practitioners who do participate are protected from civil or criminal liability. Thirdly, no family members or loved ones called upon to assist may be coerced or required to participate, but if they choose to do so, they are also protected from civil or criminal liability.

The Bill further provides for the procedures surrounding physician assisted death. Where a medical procedure is required, such as an injection or administration by gastric tube, it will be performed by an attending medical practitioner. Where a medical procedure is not required, such as taking life-ending medication orally, the attending medical practitioner may be assisted in his or her functions by another person who has been explicitly requested by the applicant to assist.

The responsible Minister will appoint a Registrar who will establish and maintain a register of End of Life Directives and Physician Assisted Deaths. It is envisaged that this Bill will fall under the portfolio of the Minister of Health. Requisite forms and certificates will be devised and promulgated by regulation.

A representative review body will be established to report to the House of Representatives on the operation of and compliance with this Bill. The purpose of this is to ensure that the Bill is working as it was designed to and to reassure the New Zealand public that it is not being distorted or abused in its application.

Bills similar to this one have been debated twice before by the New Zealand Parliament: once in 1995 and again in 2003. The first time, the Bill was defeated by 61/29 votes. The second time, it was defeated by 60/58, with the two outstanding votes consisting of 1 abstention and 1 failure to vote or register a proxy. Twelve years on, it would appear that the social conversation around this controversial issue has moved. There has been much publicity in recent times of court cases where family members of people suffering from terminal illnesses have been necessarily prosecuted for assisting their loved one to die, at their request. The courts have treated such cases with increasing leniency and compassion, as evidenced by an 18-month custodial sentence a few years ago softening to a 5-month home detention sentence more recently. Police have prosecuted such cases out of the necessary observance of current law. Public reaction to such trials has been overwhelmingly compassionate and understanding.

This Bill seeks to provide a law which prevents such convictions from occurring when the request for physician assisted death comes from the express will of the person suffering. It aims to promote compassion and the preservation of human dignity. It also reinforces the notion that someone who is an autonomous, self-determining person throughout their life should be entitled to be self-determining at the end of their life, without criminal proceedings being visited on any professionals or loved ones who might assist them.

The provisions of this Bill are not set up as an alternative to competent, accessible palliative care. This Bill is to be seen alongside the need for universally accessible, consistently high quality, palliative care. It does not contradict, but complements the right to such care. It would simply provide a legal option to those who wish to avail themselves of it.

Clause by clause analysis

Clause 1 is the Title clause.

Clause 2 is the commencement clause and provides that the Bill is to come into force on the day after the date on which it receives the Royal assent.

Part 1
Preliminary provisions

Clause 3 sets out the purpose of the Bill.

Clause 4 is the interpretation clause. It provides definitions of terms used in the Bill.

Clause 5 provides the meaning of mentally competent, and the corresponding meaning of mentally incompetent. These are key terms used in the Bill.

Part 2
Physician assisted death

Subpart 1—Entitlement to, and procedures for, physician assisted death

Entitlement to physician assistance

Clause 6 provides that a qualifying person (as defined in *clause 4*) has the option to receive physician assistance to end his or her life in certain circumstances, in accordance with the Bill's provisions.

Request made in person for physician assisted death

Clause 7 sets out how a request can be made in person for physician assistance to end the person's life.

Clause 8 requires the certifying medical practitioner to encourage the person making a request for physician assistance to end his or her life to consult with family or friends, and to seek counselling. The medical practitioner must also point out that the person is not obliged to consult family or friends.

Clause9 provides for a certificate to be made by a certifying medical practitioner regarding matters specified in *clause 9* that are relevant to the person and his or her request.

Clause 10 requires a second medical practitioner to provide a confirming medical certificate.

Request made through End of Life Directive

Clause 11 allows a mentally competent person to make an End of Life Directive that will come into effect when the person becomes mentally incompetent but is in one of the same situations that would allow him or her, if he or she were mentally competent at the time, to make a request in person for physician assistance in ending his or her life. The formal requirements of an End of Life Directive are also set out in *clause 11*.

Clause 12 provides for a certificate to be made by a certifying medical practitioner regarding matters specified in *clause 12* that are relevant to the person and his or her End of Life Directive.

Clause 13 sets out how an End of Life Directive may be registered in the register of End of Life Directives and Physician Assisted Deaths, and what the Registrar does after the Directive is registered.

Clause 14 provides the procedures for a person to cancel or vary his or her registered End of Life Directive.

Clause 15 provides for the expiry of an End of Life Directive 5 years after it is registered, and for the Registrar to give 12 months' notice of the expiry date. An End of Life Directive does not expire if the person to whom it relates becomes mentally incompetent before the date on which notice of the expiry date would otherwise have to be given.

Clause 16 sets out how a registered End of Life Directive can be renewed.

Clause 17 allows for a person to name an advocate in an End of Life Directive. The advocate's role is to ensure compliance with the Directive, in the ways set out in *clause 17*.

Clause 18 provides for a certificate to be made by a certifying medical practitioner when a situation specified in an End of Life Directive has come about, and the Directive is to be put into effect.

Clause 19 requires a second medical practitioner to provide a confirming medical certificate for putting into effect the End of Life Directive.

Carrying out physician assisted deaths

Clause 20 sets out the prerequisites enabling lawful provision of a physician assisted death.

Clause 21 states a mentally competent person's right to make decisions about the method and other matters concerning his or her physician assisted death.

Clause 22 describes the procedures that may be involved in a person's physician assisted death, and that will vary according to the person's physical and mental condition.

Clause 23 allows a medical practitioner, at the request of the person who is to undergo the procedures set out in *clause 22*, to be assisted in the procedures for a person's physician assisted death.

After procedure completed

Clause 24 requires a report, as specified in *clause 24*, to be made to the Registrar after a procedure is completed in accordance with *clause 22*.

Clause 25 requires a medical practitioner to include in the death certificate of a person who has undergone a physician assisted death in accordance with *clause 22* the person's underlying disease or condition as the cause of his or her death.

Subpart 2—Legal consequences

General legal consequences

Clause 26 states that it is lawful to provide a person who is entitled under this Bill to receive physician assistance to end his or her life with physician assistance to do so, and provides immunity from civil or criminal liability for actions done in good faith under the Bill, despite any inadvertent failure to comply fully with the Bill's requirements.

Clause 27 specifies the right not to participate in any aspects of physician assisted deaths but requires medical practitioners and solicitors who decline to participate to provide alternative sources of physician assistance and legal advice.

Clause 28 states that contracts, including insurance contracts, are to be unaffected by the fact that death is due to a procedure under *clause 22*, and that the cause of death is to be regarded as due to the person's underlying disease or condition.

Clause 29 provides for the confidentiality of requests made in person or by means of End of Life Directives.

Part 3
Miscellaneous provisions

Offence

Clause 30 provides for an offence of altering or frustrating the wishes of a person in regard to his or her choice of physician assisted death in accordance with the Bill.

Regulations

Clause 31 is a regulation-making power for forms, certificates, and other necessary matters under the Bill.

Registrar

Clause 32 requires the Minister of Health to appoint a person as Registrar of End of Life Directives and Physician Assisted Deaths.

Clause 33 requires the Registrar to establish and maintain the register.

Clause 34 requires the Registrar to report annually to the review body established under *clause 35*, and sets out the matters that must be covered in the report.

Review body

Clause 35 establishes a review body: the End of Life Options Review Body.

Clause 36 provides that the review body is an independent Crown entity for the purposes of the Crown Entities Act 2004.

Clause 37 sets out the functions of the review body.

Clause 38 states that further provisions relating to the review body are to be found in the Bill's *Schedule*. The *Schedule* provides for the membership of the review body, its procedures, and similar matters.

Consequential amendment to Crown Entities Act 2004

Clause 39 contains a consequential amendment to the Crown Entities Act, so that the review body, as an independent Crown entity, is added to Part 3 of Schedule 1 of that Act.

Support and Consultation for End-of-Life in NZ (SCENZ)

Clause 40 establishes a body called Support and Consultation for End-of-Life in New Zealand to support and inform the medical processes and procedures in this Act.

End of Life Options Bill

Member's Bill

Contents

The Parliament of New Zealand enacts as follows:

1 Title

This Act is the End of Life Options Act **2015**.

2 Commencement

This Act comes into force on the day after the date on which it receives the Royal assent.

Part 1
Preliminary provisions

3 Purpose

The purpose of this Act is to—

(a) provide individuals with a choice to end their lives in certain circumstances; and

(b) enable the provision of physician assistance to give effect to the individual's choice; and

(c) provide for related legal and other matters.

4 Interpretation

In this Act, unless the context otherwise requires,—

applicant means a person who makes a request under **section 7**

certifying medical practitioner means a medical practitioner who provides a certificate under **section 9 or 18**

medical practitioner means a health practitioner who is, or is deemed to be, registered with the Medical Council of New

Zealand continued by section 114(1)(a) of the Health Practitioners Competence Assurance Act 2003, as a practitioner of the profession of medicine

mentally competent has the meaning given to it in **section 5**

Minister means the Minister of Health

New Zealand citizen means a person who has New Zealand citizenship as provided in the Citizenship Act 1977 **permanent resident** has the same meaning as in section 4 of
the Immigration Act 2009

physician means a medical practitioner as defined above

qualifying person means a person who is—

(a) either a New Zealand citizen or a permanent resident; and

(b) aged 18 years or over

register means the register established and maintained under **section 33**

registered End of Life Directive means an End of Life Directive that is entered into the register in accordance with **section 13(2)**

Registrar means the Registrar appointed under **section 32 request** means a request by an applicant made under **section 7 or 11**

review body means the review body established under **section 35**

solicitor has the meaning given to it by section 6 of the Lawyers and Conveyancers Act 2006.

5 Meaning of mentally competent

(1) For the purposes of this Act, a person is **mentally competent** if he or she has the ability to understand the nature and consequences of a request to end his or her life, in the knowledge that the request will be put into effect; and **mentally incompetent** has a corresponding meaning.

(2) A person is presumed to be mentally competent unless the contrary is shown.

Part 2
Physician assisted death

Subpart 1—Entitlement to, and procedures for, physician assisted death

Entitlement to physician assistance

6 Option to receive physician assistance to end life

(1) A qualifying person may receive physician assistance to end his or her life if he or she—

(a) is mentally competent; and

(b) suffers from either of the following conditions:

(i) a terminal disease or other medical condition that is likely to end his or her life within 6 months:

(ii) constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

(2) A qualifying person who is mentally incompetent may receive physician assistance to end his or her life if—

(a) he or she has a registered End of Life Directive that comes into effect on the occurrence of a specified situation; and

(b) the specified situation has occurred.

(3) Any entitlement referred to under **subsection (1) or (2)** to physician assistance to end a person's life arises only in accordance with the provisions of this Act.

Request made in person for physician assisted death

7 Request made in person for physician assisted death

(1) A qualifying person to whom **section 6(1)** applies may request physician assistance to end his or her life.

(2) A request under **subsection (1)** must be—

(a) in writing; and

(b) signed by the applicant; and

(c) confirmed in writing by the applicant no sooner than 7 days after it is signed by the applicant under **paragraph (b).**

(3) Despite **subsection (2)**, if an applicant is unable to write a request or confirm it in writing, he or she—

(a) may instead mark the written request or written confirmation with an X; or

(b) may indicate a request or confirmation by other means, and that request or confirmation may be recorded in writing by another person.

(4) No request or confirmation made under **subsection (3)** is valid unless the certifying medical practitioner certifies that he or she believes that the written record of the request or confirmation properly records the wishes of the applicant.

(5) No family member or friend of the applicant can annul the applicant's request.

8 Consultation and counselling about request

(1) The certifying medical practitioner must encourage the applicant—

(a) to consult with his or her family or a close friend about the request; and

(b) to seek professional counselling during the course of making his or her request.

(2) In performing the duty under **subsection (1)(a)**, the certifying medical practitioner must advise the applicant that he or she is not obliged to consult with his or her family or a close friend about the request.

9 Medical certificate regarding request made in person

(1) Physician assistance to end the life of an applicant who has made a request under **section 7** must not be provided unless a certifying medical practitioner—

(a) provides a certificate relating to the matters set out in **subsections (2) and (3)**; and

(b) obtains a certificate from a second medical practitioner in accordance with **section 10**.

(2) The certifying medical practitioner must certify that he or she has made appropriate enquiries and, based on those enquiries, he or she believes that—

(a) the applicant has made a valid request to end his or her life, and confirmed that request, in accordance with **section 7**; and
(b) the applicant genuinely does wish to end his or her life; and
(c) there was no coercion placed on the applicant to make the request or confirmation; and
(d) the applicant is mentally competent; and
(e) the applicant has the medical condition referred to in **section 6(1)(b)(i) or (ii)** that was specified in the request.

(3) The medical practitioner must also certify that he or she has—
(a) encouraged and advised the applicant as required by **section 8**; and
(b) advised the applicant of all other medical options available, including palliative care.

(4) The certifying medical practitioner must describe in the certificate the nature and extent of the enquiries he or she made and relied on in completing the certificate.

10 Second independent medical practitioner certificate for request made in person

(1) The certifying medical practitioner must give a second independent medical practitioner the certificate made under **section 9(1)(a)**, along with all relevant medical information that the certifying medical practitioner has relating to the applicant.

(2) The second medical practitioner must determine whether he or she agrees that the applicant has the medical condition referred to in **section 6(1)(b)(i) or (ii)** that was specified in the request.

(3) In order to do so, the second medical practitioner must—
(a) consider the material provided under **subsection (1)**; and
(b) make his or her separate enquiries; and
(c) examine the applicant.

(4) If the second medical practitioner agrees that the applicant has the medical condition referred to in **section 6(1)(b)(i) or (ii)** that was specified in the request, he or she must—
(a) complete a certificate to that effect; and

(b) give it to the certifying medical practitioner.

Request made through End of Life Directive

11 Request by means of End of Life Directive

(1) A qualifying person may request, by means of a registered End of Life Directive, to be provided with physician assistance to end his or her life if he or she is mentally competent at the time of making the End of Life Directive.

(2) An End of Life Directive must specify the situations when it comes into effect.

(3) The situations that may be referred to in the End of Life Directive are that the person becomes mentally incompetent and that, in addition, any 1 or more of the following situations also applies to him or her:

(a) he or she suffers from a terminal disease or other medical condition that is likely to end his or her life within 6 months:

(b) he or she suffers from constant and unbearable physical or psychological suffering which cannot be relieved in a manner the patient deems tolerable.

(4) An End of Life Directive must be—

(a) in writing; and

(b) signed by the person.

(5) Despite **subsection (4)**, if a qualifying person is unable to write an End of Life Directive,—

(a) he or she may instead mark the written End of Life Directive with an X; or

(b) he or she may indicate a request for that End of Life Directive by other means, and that End of Life Directive may be recorded in writing by another person.

(6) An End of Life Directive made under **subsection (5)** that is not signed by the person to whom it relates is not valid unless a medical practitioner certifies that he or she believes that the written record of the End of Life Directive properly records the wishes of the person.

12 Certificate regarding request made by means of End of Life Directive

(1) When the qualifying person to whom an End of Life Directive relates signs the Directive, or is regarded under **section 11(5)** as having made an End of Life Directive, a medical practitioner or solicitor must certify that—

(a) the person was mentally competent when making the End of Life Directive; and

(b) the person wishes to end his or her life when he or she becomes mentally incompetent and any 1 or more of the situations that are referred to in the End of Life Directive also apply to him or her; and

(c) he or she has explained to the person the possible consequences of the End of Life Directive; and

(d) the person was—

(i) encouraged to consult with his or her family or a close friend about the request; and

(ii) advised that he or she was not obliged to consult with his or her family or a close friend about the request; and

(iii) encouraged to seek professional counselling during the course of making the End of Life Directive; and

(iv) advised that all other medical options would be available to him or her, including palliative care; and

(v) advised that the End of Life Directive could be cancelled or varied at any time and in any way, in accordance with **section 14**.

(2) When performing his or her duty under **subsection (1)(a)**, a solicitor must obtain the advice of a medical practitioner in respect of the person's mental competence.

13 Registration of End of Life Directive

(1) The medical practitioner or solicitor who provides the certificate under **section 12** must provide to the Registrar—

(a) the End of Life Directive; and

(b) any certificate provided under **section 11(6)**; and

(c) the certificate made under **section 12**; and

(d) the postal address of the person to whom the End of Life Directive relates.

(2) If the Registrar is satisfied that the End of Life Directive has been made in accordance with **section 11**, and certified in accordance with **section 12**, he or she must—

(a) enter the End of Life Directive in the register; and

(b) make a copy of the End of Life Directive; and

(c) note on the copy that the End of Life Directive has been registered, and the date of its registration; and

(d) send the copy to the person to whom the End of Life Directive relates at his or her postal address; and

(e) advise the person to whom the End of Life Directive relates that he or she is entitled to cancel or vary the Directive at any time and in any way, in accordance with **section 14**; and

(f) advise the person to whom the End of Life Directive relates that the Directive will expire on the day that is 5 years after the date on which it was registered, unless he or she has earlier—

(i) renewed the End of Life Directive under **section 16**; or

(ii) become mentally incompetent.

14 Cancelling or varying End of Life Directive

(1) A person who has a registered End of Life Directive may cancel or vary it at any time and in any way, by sending the Registrar a signed written notice of the cancellation or variation.

(2) Except as provided in this section, no other person (including any person who holds an enduring or other power of attorney in relation to the person to whom the End of Life Directive relates) may cancel or vary an End of Life Directive.

(3) **Subsection (4)** applies to a person who—

(a) who has a registered End of Life Directive; and

(b) is mentally competent; and

(c) wishes to cancel or vary the Directive; and

(d) is unable to write and sign a letter to the Registrar.

(4) The person may request a medical practitioner, solicitor, or the holder of a power of attorney in relation to him or her to give

notice on his or her behalf to the Registrar of the cancellation or variation.

(5) When writing to the Registrar, the medical practitioner, solicitor, or holder of the power of attorney must also—

(a) include an explanation of why he or she claims to be entitled to write on behalf of the person to whom the End of Life Directive relates; and

(b) provide a certificate from a medical practitioner stating that, on a specified date, he or she examined the person, and, in his or her opinion, the person—

(i) was mentally competent at that time; and

(ii) wished to cancel or vary the End of Life Directive.

(6) If the person writing to the Registrar under **subsection (5)** is a medical practitioner, he or she may provide the medical certificate required under **subsection 5(b)**.

15 Expiry of End of Life Directive

(1) A registered End of Life expires on the day that is 5 years after the date on which it was registered.

(2) Twelve months before the expiry date, the Registrar must write to the person to whom the End of Life Directive relates at his or her address as last known by the Registrar and notify the person of the expiry date.

(3) This section does not apply if the person to whom the End of Life Directive relates becomes mentally incompetent before the date for giving notice under **subsection (2)**.

16 Renewal of End of Life Directive

(1) A person who has a registered End of Life Directive may renew it at any time before it expires under **section 15**, by sending the Registrar a signed written notice of the renewal.

(2) Each renewal under **subsection (1)**—

(a) takes effect from the date the existing End of Life Directive would otherwise have expired; and

(b) is for a further period of 5 years from that date.

(3) Every renewal under this section must comply with the provisions of this Act.

(4) **Subsection (5)** applies to a person who—
- (a) has a registered End of Life Directive; and
- (b) is mentally competent; and
- (c) wishes to renew the Directive; and
- (d) is unable to write and sign a letter to the Registrar.

(5) The person may request a medical practitioner, solicitor, or the holder of a power of attorney in relation to him or her to give notice on his or her behalf to the Registrar of the renewal.

(6) When writing to the Registrar, the medical practitioner, solicitor, or holder of the power of attorney must also—
- (a) include an explanation of why he or she claims to be entitled to write on behalf of the person to whom the End of Life Directive relates; and
- (b) provide a certificate from a medical practitioner stating that, on a specified date, he or she examined the person, and, in his or her opinion, the person—
  - (i) was mentally competent at that time; and
  - (ii) wished to renew the End of Life Directive.

17 Role of advocate in regard to End of Life Directive

(1) The person to whom the End of Life Directive relates may name 1 or more people in the Directive whom the person appoints to act as an advocate for him or her if he or she becomes mentally incompetent.

(2) The purpose of the appointment is so that the advocate can ensure compliance with the provisions of the person's End of Life Directive, by—
- (a) ensuring that medical practitioners and other health professionals involved in the person's care are made aware of the Directive; and
- (b) ensuring that, when the Directive may become enforceable, a medical practitioner who is prepared to participate in complying with the Directive becomes involved in the person's medical circumstances; and
- (c) requesting a medical practitioner to examine the person to see if he or she is mentally competent, and whether a situation referred to in the Directive has come about; and

(d) obtain from the Registrar the expiry date of the Directive; and

(e) communicate with the review body on any aspects of the Act or the actions of the medical staff that have affected the person.

(3) A medical practitioner, hospital, or other medical or caring organisation that is satisfied that an advocate is appointed to act for a person to whom a registered End of Life Directive relates must, on the advocate's request, disclose to the advocate any information regarding the person's health or other matters relevant to the End of Life Directive, including if and when it is likely to be put into effect to end the person's life.

18 Medical certificate for putting into effect End of Life Directive

(1) Medical assistance to end the life of a person who has a registered End of Life Directive must not be provided unless a certifying medical practitioner—

(a) provides a certificate relating to the matters set out in **subsections (2) to (4)**; and

(b) obtains a certificate from a second independent medical practitioner in accordance with **section 19**.

(2) The certifying medical practitioner must certify that he or she has made appropriate enquiries and, based on those enquiries, he or she believes that—

(a) the person is mentally incompetent; and

(b) at least 1 of the situations, specified in the certificate, that is referred to in the person's End of Life Directive, has come about.

(3) The certifying medical practitioner must also certify that he or she has received from the Registrar—

(a) a copy of the person's registered End of Life Directive; and

(b) the Registrar's confirmation as to whether the Directive—

(i) is still currently registered and has not expired; and

(ii) has not expired because of the operation of **section 15(3)**.

(4) The certifying medical practitioner must describe in the certificate the medical condition of the person that he or she relied on in completing the certificate.

19 Second independent medical practitioner certificate for putting into effect End of Life Directive

(1) The certifying medical practitioner must give a second independent medical practitioner the certificate made under **section 18(1)(a)**, along with all relevant medical information that the certifying medical practitioner has relating to the person.

(2) The second independent medical practitioner must determine whether he or she agrees that the person is mentally incompetent and that the situation, specified in the certifying medical practitioner's certificate and referred to in the person's End of Life Directive, has come about.

(3) In order to do so, the second independent medical practitioner must—

(a) consider the material provided under **subsection (1)**; and

(b) make his or her separate enquiries; and

(c) examine the person.

(4) If the second medical practitioner agrees that the person is mentally incompetent and that the situation has come about, he or she must—

(a) complete a certificate describing the person's medical condition; and

(b) give it to the certifying medical practitioner.

Carrying out physician assisted deaths

20 Prerequisites for physician assisted death

(1) When certificates are provided by a certifying medical practitioner and a second independent medical practitioner under **sections 9 and 10** (which relate to a request made in person) or **sections 18 and 19** (which relate to a request made through a registered End of Life Directive), the procedure under **section 22** for a person's physician assisted death may commence and be completed.

(2) To avoid doubt, it is unlawful for the procedure under **section 22** for a person's physician assisted death to commence or be

completed unless the certificates referred to in **subsection (1)** have been provided.

21 Person's right to choose procedure for physician assisted death

(1) To the extent that it is feasible, a mentally competent person is entitled to choose the method of his or her physician assisted death.

(2) A mentally competent person also has the right to do any of the following:

(a) decide to delay the taking or administration of life-ending medication:

(b) cancel a decision to terminate his or her life:

(c) choose who will be present (apart from the medical practitioner supervising the administration of, or administering, the medication) when life-ending medication is taken or administered, who will assist in that process, and where it will take place.

22 Procedures involved in physician assisted death

(1) Subject to **subsection (6)**, before the attending medical practitioner starts any procedure for physician assisted death, the person must be advised of his or her rights and the attending medical practitioner must ask the person how he or she wishes to exercise those rights.

(2) If a person is capable of swallowing without undue discomfort, the attending medical practitioner may offer oral life-ending medication.

(3) If a functioning gastric tube is in place, the attending medical practitioner may use it to administer medication that is normally swallowed.

(4) Despite **section 21(2)(c)**, if the person is not able to self-administer a drug, or take drugs into the stomach, the attending medical practitioner must administer the life-ending medication.

(5) A medical practitioner must be present whether the patient is self administering the drug or the medical practitioner is directly administering the drug. He/she must bring the drug to the patient and if not used, must take it away and place it in safe custody. If the drug is taken by way of the stomach and death is taking some hours, he/she may leave other people to monitor the situation, but must always be immediately available to help.

15

A prior agreement with the patient may allow the medical practitioner to give extra medication intravenously, should the oral dose not be sufficient, or take too long to cause death.

(6) An attending medical practitioner may reduce or dispense with providing a person with all or part of the information that would otherwise be provided under this section, after taking into account the person's mental condition and ability to comprehend, if the person—

(a) is mentally incompetent; and

(b) has a registered End of Life Directive; and

(c) is undergoing physician assisted death in accordance with **section 20(1)**.

23 Medical practitioner may be assisted in the procedure by another person

(1) An attending medical practitioner may be assisted under **section 22**, if the person who is to undergo physician assisted death explicitly requests that other person to participate and assist in the end of life procedures.

(2) The other person has the right to refuse to assist in this way.

After procedure completed

24 Report to Registrar

(1) The attending medical practitioner must provide a report to the Registrar within 14 days after completion of a procedure for physician assisted death.

(2) The report must contain the following information:

(a) the name of the attending medical practitioner and any other attending medical staff:

(b) the name and last known address of the deceased:

(c) the place where the procedure was carried out:

(d) the date and time of the procedure, or, if that is uncertain due to self-administration, the estimated date and time:

(e) the means by which the procedure was carried out:

(f) that, in the case of a mentally competent person, the attending medical practitioner advised him or her of the person's rights under **section 22**.

(3) The attending medical practitioner must attach to the report—

(a) the certificates given by the certifying medical practitioner and the second medical practitioner; and
(b) a copy of the End of Life Directive, if the procedure was carried out pursuant to a registered End of Life Directive.

25 Death certificate

A medical practitioner who signs the death certificate of a person who has died due to a procedure under **section 22** must include the person's underlying disease or condition as the cause of death.

Subpart 2—Legal consequences

General legal consequences

26 Lawful provision of physician assistance to end life

(1) It is lawful to provide a person who is entitled under this Act to receive medical assistance to end his or her life with medical assistance to do so.

(2) A person is immune from civil or criminal liability for any act done or omission made while acting in good faith when assisting or participating in implementing any aspect of this Act.

(3) **Subsection (2)** applies despite the person having inadvertently failed to comply fully with any requirement of this Act.

27 Right not to participate

(1) No person is required to participate directly or indirectly in any aspects of this Act.

(2) A person who refuses to participate in any aspect of this Act is not required to give any reason for the refusal.

(3) A medical practitioner who is asked by a person to do any of the following, but does not wish to do so, must refer the person within two days to another medical practitioner who is not opposed to physician assisted dying and who will:
(a) advise the person of his or her rights under this Act:
(b) carry out a physician assisted death in accordance with this Act:

(c) provide a certificate under this Act.

(4) A medical practitioner who is asked by a certifying medical practitioner to complete a certificate under **section 10 or 19** as the second medical practitioner, but does not wish to do so, must immediately—

(a) advise the certifying medical practitioner accordingly; and

(b) return to him or her the material provided under **section 10(1) or 19(1)**.

(5) A solicitor who is asked to advise a client of his or her rights under this Act, or is asked to certify under this Act, but does not wish to do so, must immediately—

(a) advise the client accordingly; and

(b) refer the client to a solicitor who is prepared to advise or certify for the client.

(6) Nothing in this section applies to the Registrar in respect of his or her duties as the Registrar.

28 Contracts

(1) In any contract, including a contract of insurance, where the death of the person who has died due to a procedure under **section 22** is of relevance, the cause of the person's death is deemed to be the person's underlying disease or condition.

(2) Any insurance policy applying on the death of the person will continue to be valid if the requirements of this Act have been observed and met.

29 Confidentiality

(1) The fact that a person has made or is contemplating a request under **section 7** or an End of Life Directive is confidential to the person and any advocate appointed in the End of Life Directive.

(2) Any other person who becomes aware of that information, whether pursuant to the requirements of this Act or otherwise, must respect that confidentiality.

(3) No person is prevented by the confidentiality provided by this section from complying with any aspect of this Act.

Part 3
Miscellaneous provisions

Offence

30 Offence of falsifying or concealing, etc, intention or documents

(1) A person commits an offence who forges, conceals, destroys, or otherwise alters or frustrates the expressed wishes of a terminally ill person, or a mentally incompetent person who has a registered End of Life Directive, or any person who chooses to end his or her life in a manner that fulfils the requirements of this Act.

(2) A person who commits an offence under **subsection (1)** is liable on summary conviction to a term of imprisonment not exceeding 3 months or a fine not exceeding $10,000, or both.

Regulations

31 Regulations

The Governor-General may from time to time, by Order in Council, make regulations for all or any of the following purposes:

(a) prescribing forms to be used for the purposes of this Act:

(b) prescribing the forms of certificates to be used under this Act:

(c) providing for any other matters contemplated by this Act, necessary for its full administration, or necessary for giving it full effect.

Registrar

32 Minister to appoint Registrar

The Minister must appoint a Registrar of End of Life Directives and Physician Assisted Deaths.

33 Registrar to maintain register

The Registrar must establish and maintain a register of End of Life Directives and Physician Assisted Deaths.

34 Reports by Registrar

(1) The Registrar must report annually to the review body.

(2) The first report must be made 12 months after this Act comes into force.

(3) Each report must contain the following information in respect of the previous 12-month period:

- (a) the number of deaths carried out under this Act:
- (b) the number of those deaths that were by self-administered medication:
- (c) the number of those deaths that were by oral medication that was not self-administered:
- (d) the number of those deaths that were by other means:
- (e) the number of those deaths that were effected pursuant to an End of Life Directive:
- (f) the number of current registered End of Life Directives:
- (g) the number of End of Life Directives that were cancelled:
- (h) any other matters relating to the functioning of the Act that the Registrar believes to be of relevance.

Review body

35 Review body established

This section establishes the End of Life Options Review Body.

36 Review body is Crown entity

The review body is a Crown entity for the purposes of section 7 of the Crown Entities Act 2004.

37 Functions of review body

(1) The review body's function is to report to the House of Representatives in accordance with **subsections (2) to (4)**.

(2) The review body must enquire into and report on the following matters:

- (a) the understanding of the general public of the Act, including the rights, duties, and powers of people under the Act:
- (b) the compliance of all persons involved in granting rights under the Act:

(c) the compliance of all persons with their duties and obligations under the Act:

(d) whether the procedure for physician assisted death under **section 22** is being accomplished in a sympathetic and humane way:

(e) whether any changes to the Act are necessary or desirable to improve its operation:

(f) whether the review body is functioning as an effective organisation and whether any changes should be made to its structure:

(g) any other matters that the review body wishes to draw to the House of Representatives' attention.

(3) The review body must report to the House of Representatives within 2 months of the date on which the Registrar is required, under **section 34**, to report to the review body.

(4) If the review body has received the Registrar's report when it must report to the House of Representatives, the review body must attach to its report the information provided by the Registrar.

38 Further provisions relating to review body

Further provisions relating to the review body are set out in the **Schedule**.

Consequential amendment to Crown Entities Act 2004

39 Consequential amendment to Crown Entities Act 2004

(1) This section amends the Crown Entities Act 2004.

(2) In Schedule 1, Part 3, in its appropriate alphabetical order, insert "End of Life Options Review Body".

Support and Consultation for End-of-Life in New Zealand (SCENZ)

40 Establishment of SCENZ

(1) The Ministry of Health will establish a group of experienced participating medical practitioners who will be referred to as Support and Consultation for End-of-Life in New Zealand (SCENZ).

(2) This body will be responsible for:

(a) Forming a system to allow experienced medical practitioners on the body to act as an independent medical practitioner on request from the certifying medical practitioner for help;

(b) Creating a system of call which will not allow the first certifying medical practitioner to know who the independent medical practitioner will be;

(c) Writing standards of care and administration of drugs protocols, and advising on correct medical and legal procedures involved;

(d) Helping inexperienced medical practitioners with the actual administration of drugs where requested.

Schedule

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Further provisions relating to review body

1 Membership of review body

(1) The review body has the following membership appointed by the Minister after such consultation with the organisations, body, or office holder that the member is to represent as the Minister considers appropriate:

(a) 2 medical practitioners (one of whom must be a general practitioner) representing the Medical Council of New Zealand:

(b) 1 registered nurse representing the Nursing Council of New Zealand:

(c) 1 coroner representing the chief coroner:

(d) 1 solicitor representing the New Zealand Law Society:

(e) 1 person representing the Human Rights Commission:

(f) 1 person representing the Health and Disability Commissioner:

(g) 1 person representing the medical schools:

(h) 1 person representing senior citizens' advocacy groups:

(i) 1 person representing Māori:

(j) 1 person representing the Interchurch Bioethics Council.

(2) **Subsection (1)** applies despite section 28(1)(b) of the Crown Entities Act 2004.

2 Timing of appointments

(1) The Minister must appoint members to the review body within 6 months after the Act comes into force.

(2) The Minister must appoint any replacement member to the review body within 3 months of a previous appointee ceasing to hold office.

3 Term of office

The term of office of a member of the review body will be at the discretion of the Minister, but no person may hold office for longer than 5 years.

4 Failure to appoint or attend not to affect validity

The failure of the Minister to appoint an appointee, or the fail- ure of an appointee to attend meetings of the review body, will not affect the validity of any meeting or any other actions of the review body.

5 Procedures of review body

(1) The quorum for any meeting of the review body is at least one-half of its validly appointed members.

(2) All decisions of the review body are made on the vote of the majority of members present at the meeting.

(3) The members of the review body may appoint their own chair- person and, except as provided in this Act, may determine their own procedures.

APPENDIX 2 Example only:

END OF LIFE DIRECTIVE
Schedule ?
(as described under the End-of-Life Options Act)
(This End-of-Life Directive should be considered alongside my separate Advance Directive)

Name of person making request:

Name: ……..….

Address: …….

Date of Birth: ……

National Health Index Number ……

Should I become mentally incompetent in accordance with the definition of mental competence in Section 5 of the End-of-Life Options Act and develop one of the following conditions:

a) I suffer from a terminal disease or other medical condition that is likely to end my life within 6 months,

b) I have constant and unbearable physical or psychological suffering which cannot be relieved, and in the opinion of my advocate(s) and medical practitioner, meets my criteria for making my life unbearable (see my views below as to what sort of conditions would fulfil these criteria),

I request that I be given medical assistance to die according to the rules, procedures and safeguards outlined in the End-of-Life Options Act …….etc

The following include physical and mental conditions which I consider would make my life unbearable:

1. Severe dementia resulting from Alzheimer's disease, or degenerative brain disease due to arterial disease or other agency, where my mental competence has deteriorated to the extent that I am no longer able to recognise close relatives or friends, am dependent on others for basic physical needs e.g. eating food and drinking fluids, toileting, dressing, and have severely limited ability to communicate;

Yes No ; cross out option which does not apply**.**

2. severe brain damage resulting from injury or illness resulting in major dependence on others for basic physical needs e.g. eating food and drinking fluids, toileting, dressing, and severely limited ability to communicate;

Yes No : cross out option which does not apply.

3. severe incapacitating and progressive degenerative disease of the nerves or muscles
Yes No : cross out option which does not apply.

4. major illnesses which are making my life intolerable e.g. severe respiratory disease, poorly functioning heart, renal failure, severe stroke, paralysis from injury
Yes No; cross out option which does not apply

5. Chronic severe pain which cannot be overcome with drugs or without major sedation
Yes No; cross out option which does not apply

ADVOCATES (the number of advocates is optional but will usually be one or two)
The following persons have agreed to be advocates as described under the Act. They will be responsible for bringing my End-of -Life Directive to the attention of the appropriate Medical Practitioners.

Name:
Address:
Signature: **Date:**

Name:
Address:
Signature: **Date:**

CERTIFICATE ON SIGNING END-OF-LIFE DIRECTIVE

(This may be filled out by either a medical practitioner or a solicitor who can also act as a witness to the applicant's signature, at the time when the End-of-Life Directive is signed)

Name of solicitor or medical practitioner: ……

Address: ……

Occupation: ……..

I certify that at the time of signing this certificate:

a) the applicant was mentally competent

b) the applicant does wish the above request for medical assistance in dying to apply should they become incompetent and suffer the circumstances described above

c) I have explained the possible consequences of the End-of-Life Directive

d) the applicant has been encouraged to consult with family and counsellor

e) the applicant has confirmed advocates to act on his/her behalf should she/he become mentally incompetent

f) the applicant has been advised that other medical options are available, including palliative care

g) the applicant has been advised that while they remain mentally competent, the End-of-Life Directive can be cancelled or varied at any time by writing to the Registrar holding the document.

h) further comments:

……

……

……

……

……

……

Date: ……

Signature of person writing End-of-Life Directive: …….

Signature of medical practitioner or solicitor witnessing the above signature:

……..