Health Select Committee of the New Zealand Parliament

Petition of Hon Maryan Street and 8,974 others:

That the House of Representatives investigate fully public attitudes towards the introduction of legislation which would permit medically-assisted dying in the event of a terminal illness or an irreversible condition which makes life unbearable.

Committee Terms of Reference[1]

The petition asks for a change to existing law. Therefore the committee will undertake an investigation into ending one's life in New Zealand. In order to fully understand public attitudes the committee will consider all the various aspects of the issue, including the social, legal, medical, cultural, financial, ethical, and philosophical implications. The Committee will investigate: 1. The factors that contribute to the desire to end one's life. 2. The effectiveness of services and support available to those who desire to end their own lives. 3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation. 4. International experiences.

Christian Medical Fellowship

The Christian Medical Fellowship (CMF) was founded in 1949 and is an interdenominational organisation with over 4,500 British doctor members in all branches of medicine. We are the UK's largest faith-based professional group. A registered charity, CMF is linked to about 80 similar bodies in other countries throughout the world.

CMF regularly makes submissions on ethical and professional matters to governments and official bodies. One of CMF's aims is to promote Christian values, especially in bioethics and healthcare among doctors and medical students, in the church and in society. Many of our members are directly involved 'on the front line' in diagnosing, treating and caring for patients with terminal illnesses, as well as in supporting those with chronic irreversible conditions. We have been actively involved in the public policy debate over the proposed introduction of assisted suicide in the UK.

Submission

1. The factors that contribute to the desire to end one's life

a) Pain is not the problem – purpose and meaning are

The three main factors causing someone to turn to suicide are:[2]

---

[1] http://www.parliament.nz/en-nz/pb/sc/make-submission/0SCHE_SCF_51DBHOH_PET63268_1/petition-of-hon-maryan-street-and-8974-others

[2] http://www.nhs.uk/Conditions/Suicide/Pages/Causes.aspx

- a perception (usually mistaken) that they are alone in the world and that no one really cares about them

- a feeling (again, usually mistaken) that they are a burden on others and that people would be better off if they were dead

- fearlessness towards pain and death

Contrary to common perception, the main reason given for requesting medical assistance to die is not uncontrolled pain, nor even the fear of such pain, but the fear of loss of dignity, of becoming a burden to others, of becoming dependent. In Oregon in 2013, such existential reasons were by far the most common ones given for seeking assisted dying – 93% cited 'loss of autonomy', 89% 'loss of enjoyment of life' and 73% 'loss of dignity'[3]. 'Pain' did not figure in the top five reasons given. Similarly, in Washington in 2013, 61% of people opting for assisted suicide gave the fear of being a burden to family, relatives and caregivers as a key reason. The question is should lethal drugs be prescribed to people who feel their lives no longer have meaning and purpose?

The fact that almost a quarter of patients dying under the Oregon Act report inadequate pain control or concerns about pain also shows that palliative care provision in Oregon is unsatisfactory. This would seem to be an argument for improving standards of care rather than assisted dying.

b) Chronic illness, not just terminal illness

There is evidence that the provisions of the Oregon Act are being extended in application. Details of patients dying under the Act show a substantial number do not have terminal illnesses. In 2013 16.9% of those receiving assistance to die under the Act did not have cancer, heart disease, chronic lung disease or motor neurone disease but were classified as having 'other illnesses'. A footnote in the 2013 Oregon Public Health Division report on compliance with the Act[4] explains that this *'includes deaths due to benign and uncertain neoplasms, other respiratory diseases, diseases of the nervous system (including multiple sclerosis, Parkinson's disease and Huntington's disease), musculoskeletal and connective tissue diseases, viral hepatitis, diabetes mellitus, cerebrovascular disease, and alcoholic liver disease'.* Whilst many of these conditions might be considered life-shortening, it is not credible that all these cases were terminal, with less than six months to live. These are in the main chronic conditions, and fall outside the bounds of the Oregon Act.

c) Mental illness, especially depression

90% of those who commit suicide suffer from some form of mental illness including depression, bipolar disorder, borderline personality disorder and alcohol or drug misuse.[5] Former president of the UK Royal College of Psychiatrists Baroness Sheila Hollins, commenting on the 2013 Oregon figures[6] where less than 3% of cases were referred for a formal psychiatric assessment despite 26% meeting the criteria for depression, writes: *'Researchers have found that some patients who have*

---

[3] http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf

[4] *Ibid.*

[5] http://www.nhs.uk/Conditions/Suicide/Pages/Causes.aspx

[6] Levene I, Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. *JME* 2011;37:205

ended their lives under the terms of Oregon's assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity, it is common in elderly people and it is treatable. But in some cases in Oregon it has not been diagnosed by the doctor who assessed the patient's capacity and prescribed lethal drugs. Oregon's law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened.'

In Belgium, where euthanasia for mentally competent adults has been legal since 2002, similar incremental extension has occurred. The House of Representatives has recently voted to extend the law to cover children of any age.[7] How will it be determined whether a child's suffering is sufficiently unbearable? How will it be concluded that the child has 'the capacity for discernment' and is making a decision free from coercion? These things will be determined by the subjective opinion of a paediatrician or psychologist, in consultation with family members. It is clear that a patient who today may feel her suffering is unbearable will tomorrow, when she has had an encouraging visit from friends or relatives, or effective management of her depression, feel she can continue to cope.

It can be fiendishly difficult, even for well-acquainted family doctors, to assess the contribution that loneliness, depression or the desire not to be 'a burden' may be making to their patient's request for assisted dying. Even apparently settled wishes can change unaccountably, and apparently irreversible conditions can remit.

It is impossible to frame legislation in ways that build in effective safeguards. Although the intention in Belgium is that the provisions apply only to a small number of terminally ill children in 'unbearable' pain, experience shows that once a law is passed, its provisions are inevitably extended over time, case by case, such as to distort the original intention. Indeed, by making euthanasia available to children, Belgium's government is already extending the provisions of the original 2002 legislation. Further extension to include patients with dementia may be expected.

d) Fear of dependence and loss of control

There are able-bodied people who desperately want their lives to end – either because they have lost hope or because of what they fear might happen to them in the future. Last year, a 75 year old retired UK nurse with experience in palliative care sought help to kill herself in Switzerland. She was not suffering from a debilitating or terminal illness. The reasons she gave for wanting to end her life were that she found the reality of old age 'awful', did not 'think old age is fun', did not want to end up as a 'hobbling old lady' and because she did not want to be a 'burden' to her children. *'The thought that I may need help from my children appals me'*, she said.[8]

Cases like this illustrate the published facts from jurisdictions where assisted suicide is legal – demand for assisted suicide and euthanasia is not so much about pain, disability or terminal illness, but primarily about meaning, purpose and hope. A better response to this existential pain is to do all we can to restore hope and allay fear, by caring for the physical, social and spiritual needs of the whole person, rather than pass over a barbiturate-spiked drink or provide accompaniment for a final journey.

e) Suicide contagion and the Media

---

[7] http://www.theguardian.com/world/2014/feb/13/belgium-law-extends-euthanasia-children-all-ages

[8] http://www.thesundaytimes.co.uk/sto/news/uk_news/National/article1588630.ece

The WHO international guidelines on suicide portrayal[9] refer to over 50 published studies, systematic reviews of which have consistently drawn the same conclusion, that media reporting of suicide can lead to imitative suicidal behaviours. This phenomenon is variably termed suicide contagion, copycat suicide, suicide cluster or the Werther effect.

Its recommendations to media professionals include the following:

- Avoid language which sensationalizes or normalizes suicide, or presents it as a solution to problems
- Avoid prominent placement and undue repetition of stories about suicide
- Avoid explicit description of the method used in a completed or attempted suicide
- Avoid providing detailed information about the site of a completed or attempted suicide
- Exercise caution in using photographs or video footage
- Take particular care in reporting celebrity suicides'

Recent papers in the British Medical Journal[10] ('Papageno vs Werther Effect') and British Journal of Psychiatry[11] ('Role of media reports in completed and prevented suicide: Werther v. Papageno effects') review media coverage of suicide.

The BMJ authors note that some media coverage of suicide actually leads to a decrease rather than an increase in suicide rates: '*Newspaper items accounting for (a decrease) form a distinct non-sensationalist class of suicide reporting. They follow the recommendations of the World Health Organization in reporting suicide—for example, avoiding terms such as suicide epidemic. Our findings suggest that media reports on individual mastery of suicidal crises are highly relevant in preventing suicide.'*

In other words, media stories about how people coped positively with suicidal feelings actually lead to a decrease in levels of suicide in the general population. They name this protective effect 'the Papageno effect' in honour of the character in Mozart's opera the Magic Flute.

The BJPsych authors tested this hypothesis concluding that *'The impact of suicide reporting may not be restricted to harmful effects; rather, coverage of positive coping in adverse circumstances, as covered in media items about suicidal ideation, may have protective effects.'*

2. The effectiveness of services and support available to those who desire to end their own lives

The British Geriatrics Society (BGS) in July 2015 stated that much of the public demand for assisted dying stems from 'the fear of a prolonged death with increasing disability, sometimes associated with unwanted, burdensome medical care'.[12]

---

[9] http://www.who.int/mental_health/prevention/suicide/resource_media.pdf

[10] http://www.bmj.com/content/341/bmj.c5841

[11] http://bjp.rcpsych.org/content/197/3/234.abstract?

i) **They express concern that vulnerable older and disabled people will feel a duty to die**:
The BGS see it as their job not to *‘prolong life at all costs’* but to *‘improve quality of life’* to its natural end. They express deep concern that many requests to end life come directly or indirectly from the patients’ families and not from the older person themselves: *‘Often such requests are then forgotten if such degrading symptoms as urinary and faecal incontinence, depression and unremitting pain are relieved. The BGS is concerned with protecting the interests of vulnerable older and disabled people who already feel pressure to give up their lives to reduce the burden they feel they cause to others.’*

ii) **They argue for a change of focus**:
Suffering at the end of life can be prevented *‘by a change in the focus of care – from prolonging life to addressing the individuals own priorities and symptoms, and by the involvement of medical professionals skilled in palliative and end of life care’.*

iii) **They warn about the negative impact on doctor-patient relationships**:
that *‘crossing the boundary between acknowledging that death is inevitable and taking active steps to assist the patient to die changes fundamentally the role of the physician, changes the doctor-patient relationship and changes the role of medicine in society.’*

iv) **They appeal for a prohibition of intentional killing**:
Legalising assisted dying, they conclude, *‘will lead to a change in attitude to death in society and also within the medical profession. The prohibition on intentional killing is the cornerstone of society and it is worth preserving the notion that all lives are precious.’*

There are several factors that, when strong in a community or nation, will diminish the call for assisted suicide.

a) Better access to palliative care

Good palliative care, whether in the community or in hospices, has demonstrated that it is possible to control discomfort and distress effectively – killing the pain, not the patient.[13] In 2009 the British Medical Association (BMA), recognising that requests for assisted suicide and euthanasia are very rare when patients are being properly cared for, called for better training of doctors and education of the public about palliative care.[14] Whilst some effects of disease, such as paralysis, might not be reversible, with effective care people are still able to lead meaningful lives. The love and support of family, friends and clinical staff will affirm their value, regardless of the limitations of their condition.

The UK has benefitted enormously from the pioneering work of the hospice movement. Symptoms accompanying dying are less to be feared than at any time in history, because of medical advances and the expertise of hospice and palliative care teams. **We urge the New Zealand Government to invest greater resources in such care rather than introduce assisted dying.**

---

[12] http://www.bgs.org.uk/index.php/specialinterest-main/ethicslaw-2/4067-position-assisted-suicide

[13] Hearn J, Higginson I. Do specialist palliative care teams improve outcomes for cancer patients? A systematic literature review. *Palliat Med* July 1998,12; 5:317-332

[14] http://bmaopac.hosted.exlibrisgroup.com/exlibris/aleph/a21_1/apache_media/VITJEQ4TGE1SQBYYUCDDQ2T93SAHVT.pdf

b) Culture of equality

Of course, there is a significant cost to such care, and society must decide to value highly its sick, demented, disabled and dying members if it is to meet that cost. Legalising assisted suicide would inevitably strengthen the perception that vulnerable people have lives 'not worth living', that they would be 'better off dead', and that the costs of such care would be better directed towards healthcare provision for the more socially or economically 'productive' members of society. The quotient of compassion in the caring professions and respect for human life in society as a whole would inevitably ebb.[15]

c) Trust in the doctor-patient relationship

There are also concerns about the effect on the doctor-patient relationship of assisted dying legislation, as raised by the BGS (see above). Trust is crucial to that relationship. The patient's confidence that the doctor will always act in such a way as to do no harm is foundational to that relationship. Giving doctors the power deliberately to end the lives of their patients will inevitably redefine the nature of the relationship and risks undermining that essential trust and confidence. Doctors become hardened to causing death, and begin to see their most vulnerable patients as 'disposable'.[16] Such patients then decide not to ask for medical help, for fear that they be encouraged to consider assisted suicide by doctors whom they feel they can no longer fully trust.

Lord McColl of Dulwich described this change in medical conscience as ‘chilling’. In a speech in the House of Lords in 2003, reporting on a visit to the Netherlands, he said: *'Noble Lords will be aware that the Select Committee visited Holland. When we inquired of a doctor what it was like doing the first case of euthanasia, he said, "We agonised all day. It was terrible”. But he said that the second case was much easier and the third case – I quote – "was a piece of cake”. We found that very chilling indeed.'*[17]

3. The attitudes of New Zealanders towards the ending of one's life and the current legal situation

As a UK based organisation, we make no comment in response to this aspect of the investigation.

4. International experiences

Expectations – the difficulty of accurately predicting the future

In most jurisdictions where assisted suicide has been legalised, it has been on the basis that mentally competent adults who have a life-expectancy of six months or less could make a request for assistance.

---

[15] Wyatt J. *Matters of Life and Death.* Nottingham, England: IVP,2009 (2nd Edn):207

[16] Keizer B in Ross W. Dying Dutch: Euthanasia spreads across Europe. Newsweek, 12 February 2015

[17] McColl I. Lords Hansard, 6 June 2003: Column 1681

One of the difficulties with such a law is that it can be very difficult to estimate how long a patient with a terminal illness might survive. The Oregon experience illustrates this.[18] Some patients prescribed lethal drugs for the purpose of assisted suicide, on the basis that they were not expected to live for more than six months, had still not taken those drugs three years later.[19]

Others change their minds within that six month window. In one multi-site study in the US, half of those with terminal illness who had initially considered seeking assisted suicide changed their minds over the subsequent few months.[20]

Extension - incremental 'mission creep'

In the UK, most of the tragic cases picked up by the media involve people who are not terminally ill, and would not be expected to die within six months. Many of these patients are suffering with long-term neurological or other chronic conditions that would not have been included in the legislation proposed by Rob Marris[21] or Lord Falconer.[22] Had either of these Bills been passed pressure to extend the scope of its provisions to include such cases on grounds of 'equality' would have been inevitable. This has been seen in every European country and US state where assisted suicide and euthanasia legislation has already been passed. For example, there is clear evidence from the Netherlands that at least one thousand patients, including the elderly, incapacitated, those suffering emotional distress, the disabled and even children and new born babies, are being killed every year without their expressed consent.[23] [24] [25] Further examples are cited in the next section. As Dr Karel Gunning, a Dutch General Practitioner, states: 'Once you accept killing as a solution for a single problem, you will find tomorrow hundreds of problems for which killing can be seen as a solution.'[26]

In practice, once any so-called 'right' is established in law, experience shows that incremental extension takes place over time. There is both a steady increase in absolute numbers of cases and also inclusion of those who are outside the stated boundaries of the law. There is also pressure to extend the law as activists bring new cases to the courts using the same general arguments of autonomy and compassion.

Examples – experience in The Netherlands and Belgium

In 1984, the Supreme Court in the Netherlands established a set of criteria that should be followed for a physician to cause the death of a person by euthanasia without fear of prosecution. From 1984

---

[18] Ganzini L et al. Oregon physicians' attitudes about and experiences with end of life care since passage of the Oregon Death with Dignity Act. JAMA 2001;285:2363–7

[19] Ganzini L et al. Physicians' experiences with the Oregon Death with Dignity Act. NEJM 2000;342:557–563

[20] Emanuel EJ et al. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. JAMA 2000;284:2460–8

[21] http://services.parliament.uk/bills/2015-16/assisteddyingno2.html

[22] http://services.parliament.uk/bills/2014-15/assisteddying.html

[23] Van der Maas PJ et al. Euthanasia and other medical decisions concerning the end of life. Lancet 1991;338:669–74

[24] Van der Maas PJ et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990–1995. NEJM 1996; 335:1699–705

[25] Groenewoud JH et al. Clinical problems with the performance of euthanasia and physician-assisted suicide in the Netherlands. NEJM 2000; 342:551–6

[26] Euthanasia and assisted suicide – A joint statement by doctors and lawyers. Care Not Killing, 12 October 2005

to 2002 a series of legal decisions led to a widening application of euthanasia for the hard cases, including people living with chronic depression (mental pain) to children who were born with disabilities. This led in 2001 to Parliament officially legalising euthanasia and it coming into effect in April 2002. In the same year Belgium's law came into effect permitting euthanasia for those in a 'medically hopeless' situation – the 'hard' cases.

Both these countries now give us clear demonstrations of what happens when the law is changed – even when it is done in the name of compassion. In Belgium the rate of euthanasia increased 8-fold between 2003 and 2013,[27] whilst in the Netherlands 4,829 people received euthanasia in 2013, over three times more than when then law was introduced.[28]

A frequently heard argument is that assisted suicide gives patients the chance of dying a 'good death'. However, the reality is sometimes very different. Dutch research shows that distressing complications can occur. For example, in 18% of cases the patient failed in the attempt and doctors had to intervene and kill the patient – assisted suicide became, in effect, euthanasia.[29]

The effect of the legal change has been a significant shift towards killing and as the practice has normalised so cultural attitudes have shifted. Euthanasia has now become so prevalent in Belgium that around one in every 60 deaths of patients under GP care is of someone who has *not* requested euthanasia.[30] A culture of death develops that deadens the response to these figures.

The vast majority of UK doctors oppose a change in the law, along with the British Medical Association (BMA), the Royal College of Physicians, the Royal College of General Practitioners, the Association for Palliative Medicine and the British Geriatric Society. A law making them responsible for assisting suicide would be against the Hippocratic tradition that has guided doctors for over 2,000 years and that was captured in the World Medical Association's Statement of Marbella (1992),[31] reaffirmed in 2013.

Expense – killing is cheaper than caring

Financial cost is another driver of incremental extension – it can often be cheaper to kill than to treat. At times of national financial restraint, and with the high cost of in-patient care, the temptation for authorities to 'stretch' the scope of application would be ever-present. In the UK it costs on average £3,000 to £4,000 a week to provide in-patient hospice care, but just a one-off cost of around £5 to pay for the drugs which would help a person commit suicide. Cancer treatments like chemotherapy, radiotherapy or surgery cost much more. There is clearly a financial incentive to encourage assisted dying - do we really wish to place that temptation before families, health ministers and local healthcare managers?

As reported by the New Zealand Life Resources Charitable Trust, Oregon already has cost-caps on health care provisions. While some life-saving surgery is considered too expensive, the same

---

[27] Euthanasia and assisted suicidelaws around the world. *Guardian* 17 July 2014 *bit.ly/WmgaXm*

[28] Nearly 5000 people died via euthanasia in the Netherlands in 2013. *DutchNews.nl,* 29 June 2015 *bit.ly/1LU50jd*

[29] Onwuteaka-Philipsen BJ et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. Lancet online, 17 June 2003. www.image.thelancet.com/extras/03art3297web.pdf

[30] Belgian GPs 'killing patients who have not asked to die'. *Daily Mail,* 12 June 2015 *dailym.ai/1GBJJtk*

[31] http://www.academiavita.org/_pdf/others/wma/Ass_Suicide.pdf

provider company will front up with the money for a much cheaper alternative, assisted suicide. The company can then claim the patient 'chose' this option.[32]

Exit this way – the pressure to choose death

Thus the pressure on vulnerable people to end their lives, to 'do the decent thing' perhaps in order to liberate finances for other members of the family, becomes almost irresistible – a 'right to die' rapidly becomes a 'duty to die'.[33] It is not surprising that those campaigning for the rights of persons with disabilities are outspoken critics of such proposed legislation. It appears to say: 'yours is a life not worth living; you would be better off dead'.

Exaggeration – distortion by media

The UK media gives the impression of large numbers of people making one way trips to Switzerland to end their lives at the Dignitas facility. Their significance has been magnified in a hugely disproportionate way by the media. If fact several have gone to Zurich accompanied by television news teams or have planned their deaths at strategic moments in the campaign in an almost cynical attempt to influence public opinion and place pressure on decision-makers. Most also did not need assistance to end their lives. And most notably not one relative or helper has so far been prosecuted. The reality is that just 273 cases in the 16 years from 1998 to 2014 – fewer than 20 a year, have made the trip to Switzerland. Although each individual case is a tragedy, the numbers are tiny when compared with the 500,000 people who die in Britain each year from all causes and the 1,300 and 15,000 annual assisted suicide deaths we could expect under equivalent laws to those currently in place in Oregon and the Netherlands respectively.[34]

Existing legal provision – 'don't fix what ain't broke'

Under current UK law 'encouraging or assisting a suicide' is a crime carrying a *discretionary* sentence of up to 14 years imprisonment. The maximum sentence is virtually never given but the strong penalties it holds in reserve act as a strong deterrent to exploitation and abuse as evidenced by the tiny number of people breaking it. Those who are convicted and sentenced generally go to prison for far less than 14 years, or do not receive a custodial sentence at all.

The existing law is also being exercised compassionately as the discretion it gives to judges and prosecutors means that only two people have so far been convicted and sentenced under it in the last five years. And neither of these received the maximum sentence.

Having a clear strong and simple law like this offers protection for disabled, sick and elderly people from those who have an interest, financial or otherwise in their deaths. Of course it does mean that those who wish to push its boundaries and break it – for whatever reason – run the risk of a police investigation, a prosecution and a possible custodial sentence. But this is a very small price to pay given the protection that it offers. The reality is that Britain's law on assisted suicide is clear and right as it stands and is working well. We encourage the New Zealand government to follow Britain's example and resist the legalising of assisted suicide.

---

[32] http://www.life.org.nz/euthanasia/euthanasiapoliticalkeyissues/economics/

[33] http://www.telegraph.co.uk/comment/personal-view/4736927/Right-to-die-can-become-a-duty-to-die.html

[34] http://www.cmfblog.org.uk/2015/08/11/britains-law-on-assisted-suicide-is-not-broken-and-does-not-need-fixing/

RJT December 2015