SUBMISSION TO THE SENATE STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL AFFAIRS

Re the Inquiry into the Rights of the Terminally Ill (Euthanasia Laws Repeal)Bill 2008

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On behalf of Dying With Dignity Victoria

*** I would like to appear before a hearing if one is held in Melbourne.**

INQUIRY into the RIGHTS OF THE TERMINALLY ILL (EUTHANASIA LAWS REPEAL) BILL 2008

To the STANDING COMMITTEE on LEGAL and CONSTITUTIONAL AFFAIRS

IT IS 11 YEARS SINCE THE EUTHANASIA LAWS REPEAL BILL WAS DEBATED. ITS OBJECT WAS TO OVERTURN THE RIGHTS of the TERMINALLY ACT (ROTI), WHICH WAS THE FIRST LEGISLATION IN THE WORLD TO LEGALISE VOLUNTARY EUTHANASIA (VE).

A LACK OF INFORMATION IN 1997

There was therefore no specific information or evidence as to the effects of such legislation in practice in the community. The only empirical evidence was from surveys of the attitudes and practices of anonymous medical practitioners, and two studies from the Netherlands where VE was illegal though practiced but not punished, provided accepted medical guidelines were followed. It should be noted that in this situation, the doctor assisting with voluntary euthanasia was admitting to breaking the law, and then **hoping** that his interpretation of the guidelines was correct- he was acting under some duress The debate of the Senate therefore took place in an absence of valid information.

LEGISLATION PASSED AND ANALYSED SINCE 1997

SINCE 1997, LEGISLATION ALLOWING VE HAS BEEN PASSED IN OREGON (1997), THE NETHERLANDS (2002) AND BELGIUM (2003). Practice in those places has been carefully studied. It is no longer a matter of conjecture as to the effects on the community and the medical profession of such laws. As a result, attitudes of many significant people and bodies have changed towards acceptance of VE.

WITH THIS IS MIND, I HAVE REVISITED THE SENATE DEBATE OF 1997, AND WILL REVIEW MUCH OF THE COMMENT FROM THE PERSPECTIVE OF 2008, ILLUSTRATING MANY FLAWS OF LOGIC, AND MORE PARTICULARLY, FLAWS OF FACT WHICH HIGHLIGHTED THAT DEBATE. I WILL ALSO DISCUSS IMPORTANT INFORMATION WHICH HAS BECOME AVAILABLE SINCE THAT DEBATE.

FLAWS OF LOGIC IN SENATE DEBATE

Many speakers devoted a large part of their speeches to non-voluntary euthanasia or involuntary euthanasia, WHICH WERE NOT THE CONCERN OF ROTI. I will quote frequently from Senator Herron, a surgeon and Fellow of the Royal Australasian College Surgeons, as the first speaker, and Senator Bishop (WA) as second speaker, against ROTI, as their speeches illustrate many of the flaws in logic and misunderstanding of ROTI which marked the debate.

ROTI was quite specific – it did not allow any one to make a decision on behalf of a terminally ill person; that person alone could make the decision. Yet countless speakers ignored the word voluntary – their argument was based on those things that would happen as a result of non-voluntary euthanasia, things that were not possible under ROTI. These arguments were emotive but irrelevant. Senator Herron went so far as to draw parallels with the activities of the Nazis (p1619).

Other illogical and irrelevant argument abounded. Senator Herron claimed that the introduction of abortion would ‘inevitably lead to the legalisation of euthanasia’ (‘voluntary’ stuck in his throat again), while Senator Bishop conflated VE with capital punishment and ‘the putting to death of innocent persons’ (p1623). Senator Herron cited diagnostic errors as a reason for not allowing VE, but such possibilities did not deter him from making life affecting decisions every week of his surgical life. Such errors are, of course, far less likely when considering a terminally ill person. Senator Bishop conflated assisted suicide for the terminally ill with ‘teen suicide’, stating ‘how are they any different?’! (p1624) Then she dismissed opinion polls which had been professionally designed and administered and shown consistent results for 25 years, as asking the wrong question.

Many Senators believed that ROTI authorized State killing (Herron p1620, Bishop p1622). Bishop believed that ROTI gave ‘the State the right to sanction and authorize the killing or death of one group of citizens’ They completely ignored the fact that the State had no part in the decisions that were made by patients, supported by their doctors.. The Act allowed intolerably suffering terminally ill patients to ask their doctors for assistance to end their lives. Without a request from a patient, no one died. The doctor could refuse. The strict criteria had to be met.

Bishop went on to say that ROTI created for the State an ‘absolute right’ to ‘sanction and authorize killing’ that could be ‘extended to other groups in our society’. In other words, she was alleging that ROTI gave the State the right to extend the careful limits of the Act. Of course, it did no such thing, and could not do so without further parliamentary debate. The Parliament remains sovereign, not the State.

The passage of ROTI no more authorizes killing than does legislation authorize alcohol consumption, or freedom of religious association or contraception. In all these cases, law allows people their choice in the matter. It does not compel – it is purely facilitatory legislation, not compulsive legislation.

Again, quite illogically, Senator Bishop (p1621), describing the hard death of a relative, says ‘it would not surprise me for some to argue that **we should have hastened his death to avoid his suffering**.’ This sort of argument is the antithesis of ROTI, which only allows the suffering individual to hasten his own death, and specifically **not anyone else.** The views of others, except the doctors who may endorse the request, are irrelevant.

Further, Senator Bishop states, re her relative’s hard death, ‘I saw how all of those people drew strength from the act of sharing time with him in the final days of their father’s illness.’ Why does she imagine that the same sharing would not be equally possible under ROTI, if his death were to be assisted? Much less grief would be felt if he did not have such a hard death.

THE ‘SLIPPERY SLOPE’ – FLAWS OF LOGIC AND FACT

Many spoke of the slippery slope, believing that it was inevitable that there would be progression from voluntary to non-voluntary euthanasia. They cited findings from the first Remmelink commission re practice in the Netherlands to support this.[1] The first Remmelink report did reveal 1000 cases of non-voluntary euthanasia, and these were said to be an inevitable consequence of Dutch law. But at that time there was no Dutch law. Moreover, research showed that an even higher incidence of non-voluntary euthanasia was occurring in Belgium[2] and Australia[3], countries where VE was illegal, and there was no tacit acceptance of VE as was the case in the Netherlands. This clearly showed that non-voluntary euthanasia (NVE) was practiced in other civilized countries with advanced medical systems and compassionate doctors. One could argue from the statistics that the availability of VE in the Netherlands had actually resulted in a lower incidence of NVE.

In order to demonstrate a 'slope', two points in time are needed. A solitary study providing data is not sufficient to prove a 'slope'. With further Remmelink studies in the Netherlands[45], NVE did not increase as the critics said it inevitably would, but it decreased over time. The latest studies from the Netherlands show that VE/PAS has actually declined, while deliberate deep continuous terminal sedation has increased[6]. Continuous deep terminal sedation, without the provision of food and fluids, clearly has the ability to hasten death, is often non-voluntary, and differs only, in instances where it is clearly voluntary, from VE in the time taken to death.

LACK OF INFORMATION IN SENATE INQUIRY REPORT

Yet some, like Senator Herron scoffed at the idea that doctors were at that time 'killing by subterfuge', while Senator Bishop stated that the senate committee did not report any empirical evidence of such (p1623). How could they be ignorant of studies of Australian doctors (in Victoria in 1988[7], NSW in 1994[8], and SA in 1994[9]), WHICH INDICATED THAT AUSTRALIAN DOCTORS WERE ASSISTING PATIENTS TO DIE? Subsequently, a Queensland survey in 1997[10] again confirmed this fact. In 1998, a survey of NT doctors revealed that a majority supported ROTI[11], despite the AMA advising the Senate inquiry that there was no support from doctors. Douglas et al (2001) surveyed Fellows of Herron's own college and found that 30% had deliberately hastened death by the use of excessive doses of narcotics[12]. These doctors were not criminals, and the authorities were not hell-bent on finding them and prosecuting them. In the absence of effective law, they were doing their best to minimize suffering of the dying. Regrettably, and perhaps, dangerously, this was happening without any professional guidelines or scrutiny.

SUPPORT BY PROFESSIONALS

Senator Herron stated 'that it is important to note that the Australian Medical Association, the nursing profession and the overwhelming majority of the caring professions are opposed to euthanasia'. Senator Bishop noted that the AMA was 'strongly opposed to the legalization of euthanasia' (the ROTI legalized **voluntary** euthanasia, a fact ignored by speaker after speaker). The AMA represents only 40% of doctors, and has never had a plebiscite of it members on this issue. In 2002, one third of the members of its Federal Assembly supported a position of neutrality towards VE. This does not represent 'strong opposition'. In 2007, the Academy of Hospice and Palliative Care Medicine changed its position from opposition to studied neutrality. In 1992 78% of Victorian nurses favored law reform[13], while in1997 in NSW, 80% gave support[14]. In 2008, the Victorian Branch of the Australian Nursing Federation supports legislative change to allow physician assisted dying. In the United States, the American Medical Women's Association in 2007 supports the right of terminally ill patients to hasten their death with the aid of their physician. With time and experience, expert opinion is changing since the 1997 debate.

Although Senator Herron would not acknowledge the fact, other 'medical' Senators did confirm that doctors made life and death decisions at that time, in patients' best interests, and did hasten death through the use of palliative analgesics, and the withdrawal of treatment, often without explicit consent. Yet they saw nothing incongruous between allowing doctors the licence to do so without scrutiny or guidelines, and not legalizing patient's requests for similar assistance with the intense scrutiny required by ROTI Senator Herron had the cheek to describe doctors as 'more dysfunctional' than other professionals and the community (p1617), and therefore not reliable to make decisions under ROTI, and yet was quite happy for them to have alone the end of life power they currently had.

EVIDENCE FROM OREGON

In 1997, as the ROTI was being crushed in Australia, the Death with Dignity Act was passed in Oregon USA. It allowed terminally ill patients to request medication from their doctor to end their own lives – it had similar safeguards to ROTI. Its opponents raised similar arguments to those of the Senate. It is still operating successfully 10 years on, without any evidence of abuse. The deaths under the Act are reported and analysed annually.[15] None of the dire consequences predicted have come about. It was alleged that it would harm palliative care - the use of PC in Oregon has grown and aid-in-dying has been accepted by hospice. It was alleged that the poor, uneducated and uninsured would be forced to seek aid in dying due to lack of health care. This did not happen. The vast majority of patients have had some tertiary education, were insured and were receiving hospice care. Hospice professionals in Oregon do not see palliative care and VE as mutually exclusive. More people die at home, with higher utilisation rates of analgesics and hospice in Oregon than most other States in the USA. Daniel Lee, a Catholic philosopher, and initial opponent of the Act, recently stated "it is significant that the Oregon experience to date (2001) in no way suggests that a slide down a slippery slope is imminent."[16] That opinion remains intact in 2008. He went on "when all things are considered, the arguments in favor of prohibition of physician-assisted suicide are not particularly compelling". In 2008 there were 49 deaths via this Act in Oregon, less than 1.5 per 1000 deaths, a negligible increase over 10 years.

The 11 years that have elapsed since the Andrews Bill have provided evidence of safety in the application of legislation like ROTI. The Dutch legislation is supported by over 90% of Dutch citizens. Patients have not lost trust in their doctors. In Belgium, the parliament is considering expanding the indications for VE as they were initially too restrictive. Such change is being considered through parliamentary debate, not a 'slippery slope'. The communities where assisted dying has been legalized have not suffered a moral implosion.

DEFICIENCIES OF PALLIATIVE CARE

Many Senators extolled the virtues of palliative care. Senator Bishop stated (on the report of a Dr Smith) that ‘with few exceptions, organic problems such as pain, nausea, vomiting, constipation and depression can be handled satisfactorily’. The palliative care literature shows this is nonsense. Palliative Care Australia acknowledges that it cannot relieve all pain and suffering, even with optimal palliative care. Very common and distressing symptoms such as weakness, lack of energy, lack of appetite, drowsiness, difficulty concentrating and sadness cannot be palliated.[17] [18] While much pain can theoretically be alleviated, reports show that in practice this does not happen. Breathlessness is exceptionally difficult to treat without depressing respiration and hastening death. The refereed palliative care literature is replete with evidence of these difficulties in dealing with the physical suffering, let alone the probably more important **psychological and existential suffering**, which is even more difficult to treat. This latter suffering is important because it is frequently cited as the principal reason for a request for VE, in conjunction with physical symptoms. While the quoted figure of 5% (for unrelieved symptoms) may seem like a small number, it amounts to some thousands of people every year in Australia. It is these people who request physician assisted dying, not the 95% who may not have severe suffering, or whose suffering can be relieved. Those who cannot be helped to their satisfaction should not be ignored – their freedom, their right to choose the time and manner of their death is just as important as the other 95%.

More and more experienced palliative care physicians are confirming that palliative care is not an adequate answer for much suffering, and that assisted dying, when requested, has a place in palliative care. Senator Bishop believed that requests for VE were exceptionally rare. The report of palliative care specialist Dr Roger Hunt makes it clear that this is not so.[19]

While there have been some minor improvements in some drug treatments in palliative care, the major improvement since 1997 has been the increasing use of deep continuous terminal sedation.

CONTINUOUS DEEP TERMINAL SEDATION

Not much was known about terminal deep continuous sedation in 1997. It was not assessed in the Dutch reports of 1991 and 1996. It is now commonly used in palliative care, and it is used in exactly the same circumstances where a person might request VE, that is, intolerable and unrelievable suffering.[20] A recent report in the British Medical Journal showed that the use of deep sedation had increased in the Netherlands to 8.3% of deaths by 2005, a clear indication of the level of unrelievable terminal symptoms. This treatment involves placing the patient into a continuous drug induced sleep (coma) until death, commonly without the provision of fluids. It has been dubbed ‘slow euthanasia’[21] Its undoubted advantage is that it relieves intolerable suffering, but it has two major disadvantages. It is often provided without any explicit discussion with the patient, and it may take days before death occurs. In addition there is no reporting procedure and no prescribed safeguards. Although it clearly has the effect of hastening death, it has not attracted the same intense criticism as VE, for the dubious reason that it satisfies the contentious doctrine of ‘double effect’, and it fills a great need. The first Australian paper on the matter stated that “it provided a readilyu available means of controlling symtoms where no feasible alternative previously existed”.[22]

It could be used for a patient with uncontrollable bone pain from prostate cancer, associated with the terrible wasting that accompanies that disease. Bob Dent, the first person to use ROTI was in such a state. With the aid of legal palliative terminal sedation he might have been put to sleep and died after a week. With the aid of ROTI he activated his own injection and died peacefully in 5 minutes. Terminal sedation legal, VE transiently legal due to ROTI, but not now, due to the Euthanasia Laws Act, and flawed decision of the Federal Parliament in 1997. I say flawed because most of the arguments used have been rendered invalid by the experience of the intervening 11 years. The Senate Inquiry must address why it is acceptable to deliberately put a person with intolerable suffering to sleep for days before they die, but not to allow the same person the choice for a quick death.

The Senate debate of 1997 was praised for the level of the debate. The debate may have been civilized and lacking in abuse, but it was deficient in logic, in understanding of ROTI, and in accurate information. Speaker after speaker did not understand, or deliberately misunderstood, the essence of ROTI. It empowered patients, not doctors, and certainly not the State.

Since 1997, the passage of time and the accumulation of accurate information have dismissed consequentialist arguments raised in the Senate against the safety of ROTI. Were the properly informed Senate to debate this Bill again in 2008, with logic and accurate information, it is difficult to believe that the Euthanasia Laws Act would not be repealed.

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[1] P van der Maas et al Lancet 1991:338;669
[2] L.Deliens et al Lancet 2000:356;1806
[3] H.Kuhse et al MJA 1997:166;191
[4] P van der Maas NEJM 1996:335;1699
[5] A van der Heide et al NEJM 2007:356;1957
[6] J Reitjens et al BMJ 2008:14-3-08
[7] H Kuhse, P Singer MJA 1988:
[8] P Baume, E O’Malley MJA 1994:161;137
[9] C Stevens, R Hassan JME 1994:20;41
[10] M Steinberg et al MJA 1997:166;131
[11] C Cartwright et al University of Queensland 1998
[12] C Douglas et al MJA 2001:175;511
[13] H Kuhse, P Singer Aust Nursing J 1992:21;21
[14] NSW Nurses Association 11/1997
[15] Oregon Dept Human Services 3/2008 (*Oregon.gov/DHS/ph/pas/index.shtml.)*
[16] D.Lee Hastings Centre Report Jan 2003 p17
[17] J Kutner et al J Pain Symptom Management 2001:21;473
[18] J Solano, B Gomes J Pain Symptom Management 2006:31;58
[19] R Hunt at al Palliative Medicine 1995:9;167
[20] G Miccinesi et al J Pain Symptom Management 2006:31;122
[21] J Billings, S Block J Palliative Care 1996:12;21
[22] A Burke et al MJA 1991:155;485