NEW SOUTH WALES COUNCIL FOR CIVIL LIBERTIES

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Submission

to the

Senate Legal and Constitutional Committee's

Inquiry into the Provisions of the

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

"Over himself, over his own body and mind, the individual is sovereign."

John Stuart Mill, *On Liberty* (1859)

9 April 2008

1. Executive Summary

The New South Wales Council for Civil Liberties (CCL) urges the Senate Legal and Constitutional Committee (the Committee) to support the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 (the Bill or the Brown Bill).

1. If passed, the Bill would repeal the *Euthanasia Laws Act 1997* (Cth) (the Andrews Bill), and thus reinstate the power of the Northern Territory, the ACT and Norfolk Island to enact legislation similar to the *Rights of the Terminally Ill Act 1995* (NT) (the RTI Act).
2. CCL believes that the Bill will restore respect for the rights of the terminally ill in the Northern Territory to choose the time of their own death. The Bill will ensure that the terminally ill, if they so choose, can die with dignity and in a humane manner. The Bill will respect the fundamental principle that the individual is sovereign over their own body and mind.
3. CCL believes that the Bill will reinstate the will of the people of the Northern Territory, as expressed in the legislation of their democratically-elected Parliament. The effect of the Andrews Bill was to re-criminalise voluntary euthanasia in 1997. CCL believes that this was an inappropriate and disproportionate exercise of the Parliament's constitutional power to legislate for the Territories. The Andrews Bill imposed the will of the Commonwealth in an area where Territorians can legitimately make decisions for themselves.
4. The RTI Act did not breach any Australian or international law. Of course, the Commonwealth had a legitimate concern to ensure that the RTI Act regulated voluntary euthanasia in order to guard against abuse, misuse and undue influence. However, the outright repeal of the RTI Act was a disproportionate response to that legitimate concern.
5. CCL notes that the UN Human Rights Committee has found that a system of voluntary euthanasia does not necessarily violate the human right to life. The UN Committee stresses the importance of implementing strict safeguards against abuse, misuse and undue influence by third parties. CCL notes that the legislative scheme introduced by the Northern Territory is carefully drafted and implements the safeguards recommended by the Human Rights Committee.
6. To deny terminally ill persons their entitlement to die when they are in severe pain is cruel. CCL urges the Senate Committee to support the Bill, to vote to restore the RTI Act and the will of the people of the Northern Territory, and leave individuals once again sovereign over their own bodies.

2. The case for the RTI Act

In essence, the RTI Act regulates medically-assisted voluntary euthanasia, under very strict conditions, for terminally-ill mentally-competent adults for whom palliative care is no longer an option. Improper conduct under the Act is punishable by up to 4 years imprisonment. The safeguards are extensive and require the consensus of two doctors and a psychiatrist.

The NT law is a well-considered response to a community need. The law does not violate the rights of the individual. The law addresses, in an appropriate manner, community concern about abuse, misuse and undue influence.

The principal argument for legalising voluntary euthanasia is that a terminally-ill adult should have the right to choose to end their own suffering. The RTI Act recognises that right. As CCL Vice President, Ms Pauline Wright, explained to the Committee in 1997:[1]

> Those who are terminally ill, and who wish to, ought to have the choice to terminate their own lives with the assistance of medication. ... The moral argument that is most often advanced is that there is innate value in a human life. That is very hard to argue with. That is, of course, true. But so is the proposition that a person is in such suffering that they can no longer stand their life. Why should they be denied the right to terminate that life in a way that is as easy as possible? It is their choice. If they choose that, we ought not deny it to them. It all comes down to choice. If a person disagrees with voluntary euthanasia for a religious reason, whatever reason it might be, that person does not have to exercise the right, but I don't think they should impose that moral or religious view - whatever their view might be - on those who do wish to die.

The principal argument is backed up by arguments supporting the principle of autonomy. The most famous of these is that of John Stuart Mill, who argues in *On Liberty* that:[2]

> ...the sole end for which mankind are warranted, individually or collectively in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilised community, against his will, is to prevent harm to others...Over himself, over his own body and mind, the individual is sovereign.

[1] Senate Legal & Constitutional Committee, *Consideration of Legislation Referred to the Committee: Euthanasia Laws Bill 1996* (March 1997) [6.13].
[2] J.S. Mill, 'Liberty', in *Utilitariansim, Liberty, Representative Government*, Everyman, London 1962 pp. 72ff.

Mill's arguments are consequentialist in nature. But the principle can also be argued for on non-consequentialist grounds. If we ask what it is about us that makes us of significance—why we count in ways that animals do not, for example, or why it is in general wrong to kill us, the only answers that make sense are that we reason, and from our reasoning we choose the values by which we will live and die, and we can act on those values. It is as autonomous beings, thus understood, that we have our value.[3]

Subject to the harm principle, it is wrong to determine the values by which another person must live, for that is to deny him or her what is of ultimate importance, what makes him or her count. It is especially wrong to determine for another person the values by which he or she must die.

2.1 Case Studies

> "Dying is personal. And it is profound. For many, the thought of an ignoble end, steeped in decay, is abhorrent. A quiet, proud death, bodily integrity intact, is a matter of extreme consequence."
>
> Justice Brennan (US Supreme Court)[4]

Here are two real case studies.[5]

Patient One. In 2000, the patient had a bone infection which was widespread after a misdiagnosis of gout. Attempts to stop the infection with antibiotics led to his kidneys ceasing to function. He was admitted to a prominent Catholic hospital, where efforts to restart his kidneys failed. His death was seen to be inevitable. The pain caused by a single kidney malfunctioning is excruciating. He suffered from two, and from the bone infection as well. All efforts at pain relief failed. He was in agony, for some days. This life-long conservative Catholic begged everyone—medical staff, his relatives and friends, to end his life. He was told 'you know we can't do that'. At last, he was given a sufficient dose of morphine, and died soon afterwards.

Patient Two. Suffering from pancreatic cancer, the patient was told near the end of 1997 he had a few months only to live. He was admitted to a hospice, where his pain was treated with morphine mixtures. Although he was kept from severe pain, he suffered instead from nausea and other unpleasantness. He repeatedly declared that he felt dreadful, and wanted to die. Soon after, his medication was changed, and he died within 48 hours.

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[3] If it is asserted that we are made in the image of God, and that is the source of our value, then we may ask what it is to be in the image of God. Again the only answers that make sense refer to our ability to determine what is right and what is wrong, to choose which we will live by, and to act accordingly.

[4] *Cruzan v Director, Missouri Department of Health*, 497 U.S. 261 (1990)

[5] Real examples have advantages over hypotheticals and generalised argument—they are not purely theoretical, and the circumstances are known. For privacy and legal reasons the identity of these two patients have been suppressed, but verification can be provided with a *bona fide* request to the office of the NSW Council for Civil Liberties.

It is clear that, in these two cases, the desire to die and the patients' views that their lives were unbearable are rational. These are positions the patients are entitled to take and implement without interference from others.

2.2 Territory Rights

CCL believes that the Andrews Bill was a breach of the civil liberties and political rights of Northern Territorians because it imposed on them the will of the Commonwealth in an area where Territorians can legitimately make decisions for themselves.

The effect of the Andrews Bill was to re-criminalise voluntary euthanasia in the Northern Territory. CCL believes that this was an inappropriate and disproportionate exercise of the Parliament's constitutional power to legislate for the Territories.

The RTI Act did not breach any Australian or international law. Of course, the Commonwealth had a legitimate concern to ensure that the RTI Act regulated voluntary euthanasia in order to guard against abuse, misuse and undue influence. However, the outright repeal of the RTI Act was a disproportionate response to that legitimate concern.

CCL also notes the comments of the Gilbert+Tobin Centre of Public Law in its submission to the present inquiry[6] advising the Committee to recommend that the Northern Territory parliament pass the RTI Act again to ensure that it is legally valid. CCL endorses that advice.

2.3 Some suggestions for improving the RTI Act

Perhaps the Committee could also make some other suggestions to the Northern Territory Parliament, which might help to allay the fears of some of the RTI Act's critics who reside outside of the Northern Territory.

The RTI Act reproduces certain sections of the Death With Dignity Act (DWDA) Oregon USA virtually word for word, for example *Effect on construction of Wills contracts and statutes, Insurance or Annuity policies and Immunities (the first three)*.

The RTI Act does not, however, reproduce the "*Informed decision*" definition in 127.800,1.01 (7) of the DWDA. Though it appears to be implicit in section 7(1)(e) and (k). The RTI Act could benefit from the express inclusion of the "*Informed Decision*" definition. The definition is:

> ***Informed decision*** means a decision by a ... patient, to request and obtain a prescription to end his or her life in a humane and dignified

[6] submission 46 to the present inquiry.

manner, that is based on an appreciation of the relevant facts and after being fully informed by the attending physician of:

(a) His or her medical diagnosis;
(b) His or her prognosis;
(c) The potential risks associated with taking the medication to be prescribed;
(d) The probable result of taking the medication to be prescribed; and
(e) The feasible alternatives, including, but not limited to comfort care, hospice care and pain control.

This definition is effectively describing 'informed consent'.

The DWDA also contains the words '...who has voluntarily expressed his or her wish to die...' regarding the person seeking euthanasia. Once again this seems implicit in sections 4 and 7(1)(e) of the RTI Act, but is not express.

The 10th annual report on DWDA reveals that there were 85 prescriptions for lethal medication in 2007 with only 49 DWDA deaths in that year.[7] There have been a total of 341 DWDA deaths in the 10 years since it commenced - hardly an opening of the floodgates.

A sample of the most frequently mentioned end-of-life concerns for DWDA patients are listed in the table below.[8] They demonstrate that for those who choose to access the DWDA, the main motivations are loss of autonomy and dignity.

	2007	2006	2003	1999
Loss of autonomy due to illness	100%	96%	84%	80%
Decreasing ability to participate in activities that make life enjoyable	86%	96%	84%	67%
Loss of control of bodily function	86%	76%	47%	53%

[7] Department of Human Services, Oregon (USA), *Death With Dignity Act Annual Reports*, <http://www.oregon.gov/DHS/ph/pas/ar-index.shtml>.
[8] all reports available at: <http://www.oregon.gov/DHS/ph/pas/ar-index.shtml>.

3. Weak arguments against euthanasia

CCL notes eight arguments used to justify the State interfering with the individual's sovereign right of the terminally-ill to choose the time of their death with dignity. Many of these arguments were presented to the Senate Committee in 1997 and will probably arise again in this inquiry. CCL offers the following observations on those eight weak arguments. Some of these observations refer back to the earlier case studies.[9]

One: It has been argued that people who wish to be killed swiftly rather than to undergo the suffering and pain involved with their deaths lack courage. The assertion is itself a cowardly attack on the integrity of people dying in agony. If there were some point in their continuing to live—a close relative, perhaps, hurrying to be reconciled before it is too late, we might praise the patient's courage in not accepting a quick and easy death. Without such a point, it makes no sense to talk of courage.[10]

Two: It has been argued that life is a gift from God, and that to kill yourself is to throw the gift back in God's face. We might ask, in what sense was the last week of Patient One's life a gift? Would we say that the relief of pain is wrong, because God has given us the gift of pain? The argument is absurd—and supposes that God is a scoundrel.[11]

Three: It is argued that it is God who should determine the time a person dies, and that for the person herself (or someone acting for her) to do it is to play God. In response, it should be enough to note that the argument implies that we should not save a life that God has determined should end. Yet the argument keeps being brought up, as it was in 1997.

Four: It is argued that to legalise voluntary euthanasia is to change the role of the doctor. Doctors are concerned with saving lives, and for them to be asked to take lives instead changes how they perceive themselves, and how others perceive them. People, it is said, will not trust doctors who are known to kill.

First, a doctor should be committed above all to the welfare of her patient. Mostly, that will involve improving the quality of life, as well as lengthening it. Sometimes there is a choice between quality and length, and the choice is given to the patient. A patient may decline a particularly onerous or unpleasant course of treatment. The role of the doctor is to discuss the options and their consequences, and to help to improve the life the patient has chosen, not to determine the course of life of the patient.

[9] see p.4 above.
[10] You do not show courage by lying down on a busy road and waiting for a bus to run over you.
[11] It is also inappropriate that a law should be based on the assumption that God exists.

Second, how do people perceive a doctor who refuses to relieve intense suffering? Will they trust such a person? Will they not rather trust someone who puts their welfare first?

Third, it is sometimes the role of a doctor to decline to lengthen life, when there is absolutely no point in doing so.

Five: It is argued that modern methods can relieve pain, allowing patients to die free from it. That is true of some illnesses. It was not true for Patient One. Moreover, our bodies get used to drugs, so that they become less and less effective. And as Patient Two's case illustrates, even when pain is relieved, a patient may still not find what is left of life is worth living.

Six: It is argued that if we allow the "easy" option of voluntary euthanasia, researchers will not make the effort they otherwise would to improve palliative care, both by relieving pain and by reducing or eliminating the side effects. This supposes that we should require patients to suffer intense pain, so that others will do what they ought to be doing anyway. This is obnoxious: a denial of the moral significance of the person, who is to be used, contrary to his or her own values, for others' benefit. This view also presupposes that everyone will choose voluntary euthanasia.

Seven: It is argued that allowing euthanasia will be the thin edge of the wedge. Once we accept that there are circumstances in which terminally ill persons may choose to die, we lose the certainty offered by the universal principle that life is always precious, and that it is therefore wrong to take life. We will then be forced, as a matter of logic, to accept other cases that are clearly morally wrong.

The thin edge of the wedge argument is an argument about logic. R.M. Cornford calls it 'the doctrine of the dangerous precedent'.[12] It is, as he notes, invalid. If there is a real moral difference between two cases, accepting that one is permissible does not in any way commit us to the other. Each case should be accepted on its own merits.

In any case, it is already widely accepted that there are exceptions to the principle that it is wrong to take life. Members of the French Resistance, for example, who took suicide pills rather than reveal secrets to the Nazis, are praised for their courage. The recent case[13] of conjoined twins known as Jodie and Mary, who were separated in an operation which involved Mary's death (this being the only way either could survive) is a second example. Despite the acceptance by many people that these actions were justified, there has been no attempt to justify more doubtful cases on that basis.

Eight: The slippery slope argument, by contrast, is a causal argument. It declares that once voluntary euthanasia is legalised for the obvious cases, we

[12] Microsomographia Academica.
[13] In London, in 2000.

will move inexorably towards permitting killing in less clear cases, and that society will come to accept cases which it should not. The issue is why we should accept the assertion that we will be caused to move in the way described. No historical examples have been shown to support it. The assertion that there is a slippery slope is a mere hunch, a guess.

4. Human Rights and the Right to Life

The UN Human Rights Committee has examined the issue of voluntary euthanasia in the context of the right to life, which is guaranteed in Article 6 of the *International Covenant on Civil and Political Rights* (ICCPR), and Dutch euthanasia laws.[14]

Significantly, the Committee did not find that a system of voluntary euthanasia violates the right to life *per se*. However, it stressed that strict procedural safeguards are required to ensure against abuse and undue influence and against the application of the system to anything other than extreme cases. The Committee expressed concern about the application of such laws to children aged 13 and over.

The Committee required the Netherlands to "ensure that the procedures offer adequate safeguards against abuse or misuse, including undue influence by third parties", to strengthen the pre-death safeguard procedures and to monitor closely the operation of the law.

The carefully considered analysis of the UN Human Rights Committee demonstrates that voluntary euthanasia is not necessarily contrary to the human right to life. The legislative scheme introduced by the Northern Territory is carefully drafted and does not offend the principles laid down by the UN Human Rights Committee to safeguard against abuse, misuse and undue influence.

5. Terminology

Distinctions are routinely made in the literature on euthanasia between active and passive euthanasia and between voluntary, non-voluntary and involuntary euthanasia. Active euthanasia is doing something which speeds the death of a dying person who is suffering intolerably. Passive euthanasia is allowing a person to die, because they are suffering intolerably.

Voluntary euthanasia is done because the person wants it. Non-voluntary euthanasia is done when the person is unconscious and cannot be asked for

[14] UN Human Rights Committee, *Concluding Observations: Netherlands* (2001) UN Doc CCPR/CO/72/NET; quoted in Sarah Joseph, Jenny Schultz & Melissa Castan, *The International Covenant on Civil and Political Rights: cases, materials & commentary* (2004, 2nd ed) [8.58]-[8.59].

his or her decision.[15] Involuntary euthanasia would be something done in spite of the person's wish to stay alive, or a refusal to take action that would keep a person alive, when they want that action taken.

Because the RTI Act is concerned only with voluntary active euthanasia, this submission has been concerned with the arguments for and against making it legally permissible in appropriate circumstances.

However, the distinction between non-voluntary and involuntary euthanasia is important—and was not well understood (or deliberately confused) by some of those who gave evidence to the Legal and Constitutional Committee in 1997 (the 1997 Committee).

[15] Patients in advanced stages of dementia, for instance, are allowed to die of pneumonia, which a simple course of antibiotics would cure.