STATEMENT BY FAMILY FIRST

1.1 Family First opposes euthanasia and believes people with suicidal thoughts do not need lethal help, but life-saving assistance.

1.2 The *Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008* is intended to overturn the Federal Government's ban on both the Northern Territory and the Australian Capital Territory having laws to allow euthanasia. It also aims to reinstate the NT's 1995 euthanasia law. Family First opposes the Bill because:

- Legalised euthanasia puts pressure on vulnerable people, who feel they have to justify their existence, because they know their continued illness is putting a strain on family and friends;

- The safeguards in the NT's euthanasia legislation, which operated for nine months in 1996-97, failed on a number of occasions to protect people, who were suffering depression or who may not have been terminally ill, from a lethal injection;

- The NT's euthanasia legislation caused fear in the Territory's Aboriginal population and discouraged people from seeking medical assistance;

- Territories, which represent relatively small numbers of people, should not pass laws on such a contentious issue as euthanasia, which have an impact on all Australians, without there being a broad national consensus;

- It is generally agreed that the Bill would not achieve its objectives and may cause uncertainty in the law.

How did the NT *Rights of the Terminally Ill Act 1995* operate in practice?

1.3 The euthanasia law, the *Rights of the Terminally Ill Act 1995*, operated in the Northern Territory for nine months in 1996-97 and during that time four people died by lethal injection.[1]

1.4 David Kissane is Professor of Psychiatry at Cornell University and during 1996-97 when euthanasia operated in the Northern Territory he was Professor and Director of Palliative Medicine at the University of Melbourne. He is arguably the leading authority on the operation of euthanasia in the Northern Territory, having published numerous articles documenting the NT's experience.[2]

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1 Kissane, D, Street, A and Nitschke, P (1998) Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet*, Vol 352, page 1101

2 Professor Kissane, submission 589

1.5 Professor Kissane found that "… four of the 'Seven deaths in Darwin' revealed prominent features of depression, highlighting its strong role in decision-making by those seeking euthanasia. Alarmingly, these patients went untreated by a system preoccupied with meeting the requirements of the [euthanasia] Act's schedules rather than delivering competent medical care to depressed patients."[3]

1.6 Professor Kissane argued that:

> The brief period of legalised euthanasia in Australia provided a useful window of opportunity to view the experience of such a social experiment. Despite considerable legislative effort to draft safe regulations that would protect the vulnerable, review of the clinical accounts of patients that sought access to this legislation revealed blatant failure of the Act to achieve its purpose. Given the level of error rate that does occur in medical practice, this experience suggests it would be impossible to safely legislate for doctors to kill. Certainly the gatekeeping roles designed by this Act failed to protect depressed, isolated and demoralized patients. Cast in a legislative and bureaucratic stance, these gatekeepers ceased to practice the craft of medicine, to the neglect of the patients they sought to serve.[4]

Safeguards failed in the Northern Territory

1.7 Professor Kissane's primary concern is that there were a number of instances where what were supposed to be safeguards in the NT's euthanasia law were ignored, calling into question the safety and effectiveness of the legislation:

1.8 For example, there was a requirement in the legislation that doctors certify that a patient was terminally ill before the patient could receive a lethal injection, but the legislation did not say what should happen if doctors had differing opinions. In one particular case in the NT's experience with euthanasia:

> … one oncologist gave the patient's prognosis as 9 months, but a dermatologist and a local oncologist judged that she was not terminally ill.[5]
>
> Accurate appraisal of prognosis is notoriously difficult, particularly when the future may yet involve months or years. In this case, there was difference of opinion among clinicians regarding how terminal she was, yet no means within the safeguards to protect the misinformed patient. Wanting to end her life, she sought further opinions until someone certified what she desired.[6]

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3 Professor Kissane, submission 589

4 Professor Kissane, submission 589

5 Kissane, D, Street, A and Nitschke, P (1998) Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet*, Vol 352, page 1101

6 Kissane, D (2000), The Challenge of Informed Consent. *Journal of Pain and Symptom Management*, Vol. 19(6), page 473

1.9 The legislation also said the certifying doctor should have expertise in the patient's condition, but:

> … when an orthopaedic surgeon came forward following [Janet] Mill's public appeal for a certifying specialist, and he did not have expert knowledge of mycosis fungoides, a rare tumour involving both the skin and lymphatic systems but not the bones, this was ignored by relevant authorities. Such breaches of the Regulations were permitted by a legal system wanting to facilitate the legislation, thus removing the very safety features that had been designed to protect the vulnerable.[7]

1.10 There was other evidence that legal safeguards were seen as impediments rather than important requirements to protect patients.

1.11 For example, Section 7(1)(c)(iv) of the *Rights of the Terminally Ill Act 1995* required a psychiatrist to have "... confirmed that the patient is not suffering from a treatable clinical depression in respect of the illness" as one of the conditions before a medical practitioner was allowed to give a patient a lethal injection.

1.12 An article in *The Lancet* co-authored by Professor Kissane and Dr Philip Nitschke stated:

> Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to be overcome. PN [Philip Nitschke] understood that every patient held that view. To what extent was the psychiatrist trusted with important data and able to build an appropriate alliance that permitted a genuine understanding of a patient's plight?[8]

1.13 In evidence to the Committee, Dr Nitschke was dismissive of this safeguard in the euthanasia laws:

> The question revolved around showing signs of depression in each of the four people who made use of the Northern Territory legislation. All of them showed aspects of depression, and that, to my mind, was entirely expected. Ultimately, the question—and this was not brought out in the *Lancet* article—was: does that mean that they were so debilitated by that psychic condition that they had lost the ability to make rational thought?[9]

1.14 The danger with all legislation is that it can be seen as a list of requirements to overcome, rather than a protection against abuse of patients or against mistakes. In this case, those seeking euthanasia could try multiple doctors until they found enough signatures to meet the requirements. This became evident in Dr Nitschke's comment that "in a sense we were going through the requirements of the legislation."[10]

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7 Professor Kissane, submission 589

8 Kissane, D, Street, A and Nitschke, P (1998) Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *The Lancet*, Vol 352, page 1101

9 Dr Nitschke, Committee Hansard, 14 April 2008, page 28

10 Dr Nitschke, Committee Hansard, 14 April 2008, page 29

1.15 Dr Nitschke told *The Sydney Morning Herald* in 2005 in relation to depression that "… common sense is a good enough indicator. It's not that hard to work out whether you are dealing with a person who is able to make rational decisions or not."[11]

1.16 But studies show that "… the diagnosis of major depression in the gravely ill is very difficult. Low spirits are to be expected in serious illness, and many of the other features of major depression (such as weight loss and sleep disturbance) are also common in physical illnesses. The difficulty of diagnosis is reflected in studies that reveal that non-psychiatrically trained doctors miss up to half of cases of major depression in the medically ill."[12]

1.17 Another study confirms that "… psychological distress, including depression and hopelessness, are significantly associated with patients' interest in hastening their own death through euthanasia and/or PAS [patient assisted suicide]."[13]

1.18 The interest of depressed people in euthanasia is because they "… often focus on the worst possible outcomes and are impaired by apathy, pessimism and low self-esteem."[14]

1.19 The NT euthanasia legislation failed to protect those four people who suffered from depression, some of whom were given a lethal injection. The NT's law should not be revived as it would put more vulnerable people at risk.

Health facilities in the NT

1.20 Medical services in the Northern Territory in the year that the euthanasia bill was passed were limited, with "… no dedicated oncology unit, no radiotherapy, and no dedicated palliative care unit or hospice before the legislation was introduced."[15]

1.21 Dr David Gawler, a consultant vascular surgeon at Royal Darwin Hospital, said at the Committee's hearing in Darwin in April that medical services are still inadequate:

> There is a massive gap between the health services and health outcomes of the Northern Territory and those of southern states. This is reflected in the 17-year gap in the age of death—and it is my impression that in the town camps of Darwin the gap is much, much bigger than that. … we lack

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11 ACT Right to Life Association Inc, submission 434

12 Ryan, C (1996) Depression, decisions and the desire to die. *Medical Journal of Australia*, Vol 165, page 411

13 Emanuel, E et al (2005) Depression, euthanasia, and improving end-of-life care. *Journal of Clinical Oncology*, Vol. 23(27) page 6456

14 Ganzini, L (2000) Commentary: Assessment of Clinical Depression in Patients Who Request Physician-Assisted Death. *Journal of Pain and Symptom Management*, Vol. 19(6), page 474

15 Professor David Kissane, submission 589

> radiation therapy, neurosurgery, open-heart surgery and cardiac endovascular intervention, and patients have to travel far from family and friends and often become isolated. Some choose not to go and would rather die. We need more services.[16]

1.22 The relatively poor state of the NT's health services reinforces the conclusion that euthanasia laws are totally inappropriate for the Territory.

Aboriginal people

1.23 The NT's euthanasia law also scared many Aboriginal people away from seeking medical assistance:

> … the first time the bill was proposed in the Territory there was a lot of anxiety amongst a lot of the Aboriginal people here. A lot of our mob did not want to come into hospital for specific treatment and all that sort of stuff. The understanding of the whole bill, I think, was one of the sticking points apart from all the other fears that our people had and still have.[17]

1.24 The Aboriginal Medical Services Alliance spokesman explained:

> The thing is that, if anything, you would have people avoiding coming to the health services altogether. Any one of our old people who have got a terminal illness—although it could even be diabetes or something like that—is going to have in their mind: 'I am not going into that place because it's the same old story. I might not come out.' I guess that fear still remains with our people.[18]

1.25 Dr Gawler also offered this perspective from his experience offering medical services to Aboriginal people:

> Euthanasia may be offered to Aboriginal people because of the white perception of quality-of-life issues. Euthanasia legislation has the potential to prevent Aboriginal people from seeking health care because of the fear that they could be misunderstood, that their lives would not be valued or that they could be put down with a needle.
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> I regularly fly out to remote communities … These good relationships will be undermined by the suspicion that medical nursing staff or health workers may prefer that patients be killed rather than treated. Euthanasia taints the medical profession by introducing the dual role of killing and treating.[19]

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16 Dr Gawler, Committee Hansard, 14 April 2008, page 10-11

17 Mr McKenzie, Aboriginal Medical Services Alliance, Committee Hansard, 14 April 2008, page 32

18 Mr McKenzie, Aboriginal Medical Services Alliance, Committee Hansard, 14 April 2008, page 33

19 Dr Gawler, Committee Hansard, 14 April 2008, page 10

1.26 Medical services need to become more accessible to Aboriginal people, not less. Parliaments need to be very careful they do not adopt policies that further reduce the health levels of Aboriginal people.

Debate on allowing lethal injections

1.27 Family First believes that it is necessary to keep the prohibition on euthanasia for the common good:

> In a democratic society one's claim to liberty to do something has to be measured against the rights of others and the demands of the common good. Sometimes we cannot exercise apparent liberties because to do so would have a detrimental effect on the common good of society, and hence a detrimental effect on other innocent members of society.[20]

1.28 If euthanasia was again made legal, it would put subtle yet very real pressure on dying people:

> Legalised active euthanasia requires every dying person to consider questions like, "Should I end my life now so my estate can educate the grandchildren rather than providing me with nursing care?"[21]

1.29 People do not wish to be a burden to their family and friends, so the reaction of their loved ones is central to their seeking euthanasia:

> Acceptance of euthanasia by a family, as exemplified by case four, where five children travelled to Darwin with their mother, might subtly confirm to the patient that he or she would indeed be a burden, interfering with busy lives, and that any remaining length of life was unimportant. These unspoken messages have further profound effects on morale. Many elderly patients fear being a burden, but seek reassurance and expression of gratitude for efforts in years gone by. Families are challenged to take care that they do not misunderstand a tentative suggestion by a family member that they might be a burden. As a clinician, I believe that any patient who is convinced they are a burden has lost perception of their own worth, sacrificing their life heroically to advantage their family. Exploration of such stories invariably reveals a demoralized perspective.[22]

1.30 Ethicist Dr Nicholas Tonti-Filippini, who himself has a terminal illness, recounted his experience of feeling a burden:

> Every year I receive from my health insurer a letter that tells me how much it costs the fund to maintain my health care. I dread receiving that letter and the psychological reasoning that would seem to motivate it. Every year I am reminded how much of a burden I am to my community. The fear of being a burden is a major risk to the survival of those who are chronically ill. If

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20 Australian Catholic Bishops Conference, submission 410

21 Professor Brennan, submission 428

22 Professor Kissane, submission 589

> euthanasia were lawful, that sense of burden would be greatly increased for there would be even greater moral pressure to relinquish one's hold on a burdensome life.[23]

1.31 Northern Territory palliative care specialist, Dr Mark Boughey gave evidence that often relatives are more distressed than the person dying, which can lead to pressure for euthanasia:

> I think it is important to understand that when people are dying—this is in the nitty-gritty day-to-day process of dying—it is often not the person dying who is expressing the wish to be euthanased. Often the relatives and friends who are standing around the bedside are stressed by and distressed at seeing a loved one dying—but it is really not their dying. I think that we sometimes forget that the dying that the person wants and has expressed should be respected. It is of concern that, with a patient's loss of mental capacity and agents speaking on their behalf, undue pressure can somehow be brought to bear on relatives to act towards taking a stance on euthanasia at that stage.[24]

1.32 The Australian Medical Association points out that "no one should feel that their only option for satisfactory relief of pain and suffering is to end their own life."[25]

1.33 Former director of palliative care at Concord Hospital in Sydney, Dr Brian Pollard, said:

> I did not ever encounter, in five years of this work, any patient for whom we ran out of options. I had patients who would say to me early on, 'I want you to know that I'm in favour of euthanasia,' and I would say to them, 'Okay. You let me know when you reckon things are out of control, and we'll talk about it.' Nobody ever had the opportunity or wanted to raise it with me thereafter. The people who asked me for euthanasia were the families, the distressed relatives. They had their distress even after the patient had been made comfortable, and they would say: 'Look: see how he is suffering.' But he was not suffering any longer; they were.[26]

1.34 If euthanasia were allowed again in Australia, whatever the so-called safeguards in place, it would be some short steps from voluntary to non-voluntary euthanasia:

> … once the law crosses the moral Rubicon of state authorisation of administered death, there is no moral or ethical bar to expansion of that authorisation in the future. If the patient is no longer competent, why shouldn't the relatives be able to make the decision? Then, if there are no relatives, why shouldn't the state be able to make the decision? If the

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23 Dr Nicholas Tonti-Filippini, submission 1100

24 Dr Boughey, Committee Hansard, 14 April 2008, page 38-39

25 Australian Medical Association, submission 375

26 Dr Pollard, Committee Hansard, 16 April 2008, page 25

> patient is poor and the state under-resourced, why shouldn't the state be able to provide better, cheaper euthanasia services and spend less on palliative care procedures – rendering the 'choice' of voluntary euthanasia more attractive to the poor?[27]

1.35 Dr Nitschke in his 2005 book *Killing Me Softly* gives a good indication of the agenda of euthanasia campaigners with this comment:

> One can but wonder when a government will have the guts to stop digging the fiscal black hole that is their ever-deepening legacy for future generations. While the enabling of end-of-life choices will not fix the economic woes of the next 40 years, it would not hurt, given half a chance. So the next time you hear a government minister trying to argue why this or that payment or welfare program for single mothers or war veterans must be cut, counter their argument with their fiscal irresponsibility on end-of-life choices.[28]

1.36 The comments by Dr Nitschke are a frightening insight into the way the euthanasia debate may develop in Australia, with arguments moving from helping people with a terminal illness to saving taxpayers money.

Reports on euthanasia

1.37 A number of major national and international reports have examined euthanasia and found that it is dangerous.

1.38 The Southern Cross Bioethics Institute gave details of a study of the experience of The Netherlands with euthanasia and especially with non-voluntary euthanasia:

> The authors of the Remmelink study [detailing the Dutch experience with euthanasia] have conceded that voluntary euthanasia inevitably leads to non-voluntary euthanasia. In an essay in the Hastings Center Report, the prestigious American bioethics journal, they said:
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> "But is it not true that once one accepts [voluntary] euthanasia and assisted suicide, the principle of universalizability forces one to accept termination of life without explicit request, at least in some circumstances, as well? *In our view the answer to this question must be affirmative*." (My emphasis).[29]

1.39 The UK House of Lords Select Committee on Medical Ethics found that:

> It would be next to impossible to ensure that all acts of euthanasia were truly voluntary. We are concerned that vulnerable people - the elderly, lonely, sick or distressed - would feel pressure, whether real or imagined, to request early death. We believe that the message which society sends to

27 Professor Brennan, submission 428

28 ACT Right to Life Association Inc, submission 434

29 Dr John Fleming and Dr Gregory Pike, submission 444

> vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death, but should assure them of our care and support in life … [30]

1.40 Further, advice to the Senate in the report of the Senate Legal and Constitutional Affairs Committee inquiry into the *Euthanasia Laws Act* argued that:

> The potential for 'guilt feelings' for being a burden… may become such that they perceive a subtle duty on them to exercise the euthanasia option. The choice may well become a perceived duty. This is so especially when considered in the context of comments by those such as former Governor General, Hon Bill Hayden, that "There is a point when succeeding generations deserve to be disencumbered - to coin a clumsy word - of some unproductive burdens". [31]

1.41 Each of these reports found that euthanasia could not be kept safe and that vulnerable people would become victim to such a law.

Should territories make laws on euthanasia?

1.42 The Bill also raises the question as to whether territory parliaments should be allowed to make laws on euthanasia.

1.43 Under the *Northern Territory (Self-Government) Act*, the Territory does not have the power to pass laws relating to workplace relations, uranium mining or land rights, as well as euthanasia.[32]

1.44 The Australian Capital Territory too is not permitted under its self-government legislation, in addition to the euthanasia ban, to make laws to govern the operation of the Australian Federal Police, in relation to industrial relations and on how many parliamentarians there are in the ACT Legislative Assembly.[33]

1.45 Until there is a decision that the territories should become states, it is clear that they will not have the same powers as states and their activities will ultimately always be overseen by the Federal Government.

1.46 Professor Frank Brennan argued that:

> … I am one of the view that generally territories should be allowed to exercise the same law-making power as states. I set down what I saw as fairly clear criteria and rare circumstances for exceptions: where no state has similarly legislated, where the territory law is a grave departure from the law in all equivalent countries, where the territory law impacts on the

30 Dr David van Gend, submission 413

31 Dr David van Gend, submission 413

32 Committee Hansard, 14 April 2008, page 3

33 Mr Corbell, Committee Hansard, 16 April 2008, page 22

> national social fabric outside the territory and where the territory law has been enacted without sufficient regard for the risks and added burdens to its own more vulnerable citizens, especially Aborigines.[34]

1.47 Professor Brennan also questioned whether the Bill was drafted to reinstate the Northern Territory's euthanasia law rather than to allow the people of the Territory to re-examine the issue because there is not support for the law:

> … I am not aware of any sustained clamour from the Parliament or citizens of the Northern Territory for the repeal of this Commonwealth measure. Perhaps this explains the use of the constitutionally suspect clause (Schedule 1, s.2) purporting to resurrect the operation of the Rights of the Terminally Ill Act 1995 without the need for further legislative action by the Legislative Assembly of the Northern Territory.[35]

1.48 When the parliament of the second smallest state or territory in Australia passes a law that has an effect on the rights of all Australians without establishing broad consensus across Australia, there is a place for the Federal Parliament to intervene.[36]

1.49 Family First believes the Australian Parliament does have a legitimate role in overturning the Northern Territory's euthanasia laws and in preventing the territories from making laws on euthanasia.

Would the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008 work as intended?

1.50 It was generally agreed in evidence given to the Committee that the legislation would not achieve its purpose of reinstating the Northern Territory's euthanasia laws.[37]

1.51 It was pointed out that:

> The submissions of the Northern Territory government, the Northern Territory Law Reform Committee, the Gilbert and Tobin Centre of Public Law and the Law Council of Australia are sufficient to highlight that there is a lot of doubt and complexity here. Everyone is agreed, no matter what their view on euthanasia, that there has to be absolute certainty about the law that applies for doctors and patients in these circumstances.[38]

1.52 The Northern Territory Government was concerned that doubt over the Bill might also lead to doctors being prosecuted for giving patients a lethal injection if it

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34 Professor Brennan, Committee Hansard, 16 April 2008, page 10

35 Professor Brennan, submission 428

36 Professor Brennan, submission 428

37 eg Gilbert and Tobin Centre of Public Law, submission 46; Northern Territory Government, submission 446

38 Professor Brennan, Committee Hansard, 16 April 2008, page 9

were later found the Bill did not actually reinstate the Northern Territory's euthanasia laws. [39]

1.53 The Northern Territory Law Reform Committee also thought that the Bill may mean that the NT Parliament would not be able to amend a euthanasia law reinstated by Commonwealth law.[40]

Conclusion

1.54 Family First opposes euthanasia and believes people with suicidal thoughts do not need lethal help, but life-saving assistance. The Northern Territory's nine month experience with euthanasia demonstrated that the so-called safeguards in the legislation were not effective in protecting vulnerable people from a lethal injection. It caused fear in the Territory's aboriginal community and used the second smallest jurisdiction in the country to force the availability of legal euthanasia on all Australians. The NT's euthanasia bill should not be revived and nor should such a small jurisdiction be allowed to impose its decision on all Australians.

Senator Steve Fielding
Family First Leader

39 Mr Joyce, NT Government, Committee Hansard, 14 April 2008, page 2

40 Northern Territory Law Reform Committee, submission 443