

Submission to the Senate Legal & Constitutional Affairs Committee

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

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Supplementary material for Senate Hearing Darwin, April 14th 2008

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1. Unsafe: Dr Nitschke and the failure of 'safeguards'

This Bill before the Senate would reactivate the Northern Territory ROTI Act, and that would reactivate Dr Philip Nitschke's euthanasia clinic in Darwin. I think that would be a reckless action, given what we have observed of Dr Nitschke since 1996.

On the evidence, Dr Nitschke failed to honour the so-called 'safeguards' in the ROTI Act back in 1996; he has since continued to defy the laws against assisted suicide; he has instructed Australians how to obtain and import illegal suicide-drugs; he has deceived the public about his high-profile patients – as in the Nancy Crick case – to further his cause.

Given that Nitschke's euthanasia clinic would be back in business, how can legislators have any confidence that "safeguards" in the ROTI Act would now be observed, when they were held in contempt in 1996?

- In 1996, in the case of Janet Mills, Nitschke violated a key safeguard of the Act by failing to get a valid specialist opinion - but Janet Mills was still killed and nothing was done about it. She suffered from a rare cancer of white blood cells, and a physician would not certify that her condition was terminal. So Nitschke got a *bone surgeon* to do the certification, even though he had no expertise whatsoever in the relevant disease. As Professor David Kissane observed of this case: "The coroner of the day ignored the breaches of the Regulations."¹ If a key safeguard was successfully evaded in only the second death under the Act, under the full spotlight of public attention, how much shabbier will be the enforcement of any so-called safeguards for the hundred and-second death?
- In 1996, at least three of the patients seeking suicide were given a parody of psychiatric assessment – in one case a superficial 20 minute consultation on the day the patient was to die. How will patients with suicidal depression who present to Dr Nitschke have any better chance now of being protected from their mental disorder and treated, rather than killed, when he made no attempt to treat the obvious clinical depression, or assist with the social isolation and despair, of those presenting in 1996? A doctor's duty is to protect patients from suicide; Dr Nitschke's duty is to facilitate their suicide.
- As to the requirement that the patient be advised of all palliative measures to ease their suffering, I have on two occasions challenged Dr Nitschke to undertake some formal training in this powerful and rapidly developing field of medicine, but he rejects the suggestion. Why master the art of palliation, when you can provide the patient with lethal drugs?

The motives of doctors and the integrity of their clinical decision-making have proven difficult to assess in other jurisdictions. Taking the example of Oregon, where assisted

¹ See Kissane DW. (2002) Deadly days in Darwin. In *The Case Against Assisted Suicide*, K. Foley & H. Hendin (eds). Pp. 192-209. Johns Hopkins University Press, Baltimore. Also Kissane DW, Street A, Nitschke P. (1998) Seven deaths in Darwin: studies under the Rights of the Terminally Ill Act, Northern Territory, Australia. *Lancet*, 352: 1097-1102 (tabled for Senate Hearing).

suicide has been present for ten years, the state department charged with formulating Oregon's official reports admitted:

"For that matter the entire account [received from a prescribing doctor] could have been a cock-and-bull story. We assume, however, that physicians were their usual careful accurate selves."²

Senators might consider this question: are you prepared to "assume", in the light of the violations of the ROTI Act and the public deception over the Crick case, that future accounts of patient deaths from Dr Philip Nitschke reflect his "usual careful, accurate self"?

If not, where are the "safeguards" in this legislation?

2. Unsafe: giving the wrong message to suicidal youth

The Committee must consider the vital question as to how a culture of euthanasia will affect the tragic incidence of youth suicide.

Dr Nitschke's view of the 'right to die' includes depressed young people. He supported the right to assisted suicide for the 'troubled teen' in his interview with *National Review* in 2001:

Someone needs to provide this knowledge, training, or recourse necessary to anyone who wants it, including the depressed, the elderly bereaved, [and] the troubled teen....

This would mean that the so-called "peaceful pill" should be available in the supermarket so that those old enough to understand death could obtain death peacefully at the time of their choosing.³

He emphasized that he did, indeed, believe that children and teens should have access to assisted suicide. "Why should they have to wait till they're 18?"

Professor of Psychiatry in Brisbane, Frank Varghese, writes:

At a time when suicide rates, particularly among the young, are of considerable community concern, it seems extraordinary that (people) should be suggesting suicide as a treatment. What message are we giving people who are in despair and contemplating suicide?⁴

I asked Dr Graeme Martin, of *Suicide Prevention Australia*, for his thoughts on the implications of legal euthanasia for adolescent suicide. He wrote in reply:

2 Oregon Health Division, CD Summary, vol. 48, no. 6 (March 16, 1999) p. 2.
<http://egov.oregon.gov/DHS/ph/cdsummary/1999/ohd4806.pdf>

3 Kathryn Lopez, "Euthanasia Sets Sail," *National Review Online*, June 5, 2001.

4 Varghese F. "An end to misery, or do we fail the patient?", *Courier Mail*

As euthanasia (physician assisted suicide) gains more acceptance in Australia, I feel sure there will be an increase in those young people who challenge us to "put them out of their misery"...

Susan M. Wolf, an associate professor of law and medicine at the University of Minnesota, has warned that a discussion of the paediatric implications of euthanasia and assisted suicide is necessary for a full debate of the issues.⁵

Here, then, is a further example in which a culture of socialised suicide will harm the vulnerable amongst us – in this case, the young and depressed.

3. Unsafe: the inability to protect patients from doctors

Brisbane Professors of psychiatry, Frank Varghese and Brian Kelly, warn of the impossibility of protecting patients from doctors once doctors are allowed to be involved in a patient's suicide:⁶

Much of the debate about euthanasia and physician-assisted suicide has as its underlying assumption that doctors will always act in the interests of their patients. This assumption fails to take into account the doctor's unconscious and indeed sometimes conscious wishes for the patient to die and thereby to relieve everyone, including the doctor, of distress.

Legislation to enable assisted suicide has been designed to provide a safeguard, through psychiatric assessment, that protects patients from themselves. What these laws do not do and cannot do is protect the patient against unconscious factors in the doctor.

4. Unsafe: Leaving patients more vulnerable to untreated depression, by weakening the normal 'therapeutic relationship' with doctors

Doctors have a duty to protect patients from suicide, and treat the disordered brain chemistry of depression. Laws which give the status of a "right" to a suicidal mind-set undermine the duty – and capacity - of doctors to protect patients from suicide.

Varghese and Kelly argue that involving physicians in assisted suicide will violate the 'boundaries' necessary for a doctor to stand back from the patient and diagnose and treat depression. Therefore patients will be left untreated and vulnerable to disordered mood and suicidal ideas:⁷

Whether a physician should assist in a patient's suicide remains fundamentally a question about the framework and boundaries of clinical

5 S. Wolf, "Facing Assisted Suicide and Euthanasia in Children and Adolescents," in L. Emanuel, ed., *Regulating How We Die: The Ethical, Medical, and Legal Issues Surrounding Physician-Assisted Suicide*, 1998, 93.

6 Varghese F, Kelly B, Physician-assisted suicide, *Psychiatric Services*, April 1999, Vol. 50 No. 4

7 Varghese F, Kelly B, Physician-assisted suicide, *Psychiatric Services*, April 1999, Vol. 50 No. 4

practice. To draw a parallel, we suggest that whether a physician should engage in a sexual relationship with a patient is less a moral or philosophical issue than one of therapeutic boundaries. The therapeutic framework that implicitly and explicitly forbids a sexual relationship allows the doctor to examine the patient's feelings with the patient. Whether a patient who seeks a sexual relationship with the doctor is "competent" is not the issue.

The very presence of the prohibition against a sexual relationship makes it possible for the patient's wishes to be dealt with in a therapeutic manner. We contend that the same therapeutic framework applies to requests for physician-assisted suicide. Without a framework that prohibits the action, a doctor is not able to carefully examine the possible meanings of such a request in the total context of the patient's life, and indeed in the context of the relationship with the doctor. Such a process of therapeutic engagement is not possible within a legislative framework in which assisting suicide is a potential outcome.

Daniel Callahan, a philosopher at the Hastings Center in New York, sets limits on what doctors should be asked to do. He reflects on how assisted suicide would violate the doctor-patient relationship:

Doctors ought to relieve those forms of suffering that medically accompany serious illness and the threat of death. They should relieve pain, do what they can to allay anxiety and uncertainty, and be a comforting presence. As sensitive human beings, doctors should be prepared to respond to patients who ask why they must die, or die in pain. But here the doctor and the patient are at the same level. The doctor may have no better an answer to those old questions than anyone else; and certainly no special insight from his training as a physician. It would be terrible for physicians to forget this, and to think that in a swift, lethal injection, medicine has found its own answer to the riddle of life. It would be a false answer, given by the wrong people. It would be no less a false answer for patients. They should neither ask medicine to put its own vocation at risk to serve their private interests, nor think that the answer to suffering is to be killed by another.⁸

5. Unsafe: the 'slippery slope'

Can any legislator seriously think that euthanasia can be contained to the so-called hard cases, given the Dutch experience, and when its principle Australian advocate has made clear – as in the Nancy Crick case – that the right to die should extend to those who in fact have no terminal disease, no pain, but simply desire death – including, as he has stated elsewhere, troubled teenagers?

Professor of Politics at Latrobe, Robert Manne, comments on the impossibility of containing euthanasia:

⁸Callahan D, When *Self-Determination Runs Amok*, *Hastings Center Report*, March-April 1992, p.55.

For anyone who understands social processes the expansion of the circle of those who can be killed will come as no surprise. For once we agree to the principle of doctors performing voluntary euthanasia, by what effort of societal will, on what rock of ethical principle, can we resist its extension to ever new categories of sufferers? There is no such will; no such fixed and reliable principle.⁹

Commenting on the Dutch evidence, ethicist Luke Gormally reviews the judicial expansion of criteria for euthanasia:

From being tolerated in a few hard cases, it has gradually been extended there from voluntary to non-voluntary, from the terminally ill to the physically sick, from the physically sick to the depressed and lonely, from competent adults to the unconscious and children, from being a course of last resort to an increasingly common course for many patients.¹⁰

The House of Lords Select Committee in 1993 considered this inability to set secure limits as a strong reason not to liberalise the law:

...to create an exception to the general prohibition of intentional killing would inevitably open the way to its further erosion, whether by design, by inadvertence, or by the human tendency to test the limits of any regulation.¹¹

6. Summary:

- The principal reason to reject euthanasia laws is that they are unjust. They might enlarge the 'choice' of some, but they will diminish the freedom of others. They would lead to a society where "vulnerable and disadvantaged people will feel pressure – whether real or imagined – to seek early death". A society where "unproductive burdens" will know (in their loneliness and low self-esteem) that they are no longer welcome, and what is expected of them.
- The secondary reason is that euthanasia laws are unsafe. There is an inability to achieve meaningful safeguards, there are harmful implications for the culture of youth suicide, there will be no ability to protect patients from doctors, doctors will be inhibited in taking the necessary measures to protect patients suffering suicidal disorders, and such a radical law will lead, as it has in Holland, to further erosion of the "general prohibition against intentional killing".

⁹ Manne R, Quadrant editorial, July-August 1995.

¹⁰ Mr Luke Gormally, *"The British House of Lords - why it Rejected Euthanasia"*, address to the John Plunkett Centre, Sydney, November 10 1995. P.9.

¹¹ op cit, para. 238

Physician-Assisted Suicide

To the Editor: The November 1998 debate on physician-assisted suicide between Drs. Hartmann and Meyerson (1), followed by the paper from the Netherlands by Dr. Shoevers and associates (2), raises significant issues about how psychiatrists ought to conduct themselves if asked to assist in suicide.

Unfortunately, the debate between Hartmann and Meyerson ignores the clinical context and concentrates instead on ethical, moral, and philosophical issues. While consideration of these issues is important, we believe the narrow focus on them will not resolve the question of whether legislation should allow physician-assisted suicide. What we are left with is disagreement as to what is ethical and what is not, and a choice between different philosophical versions of the notion of autonomy of the individual. Such questions need to be placed in the clinical context, specifically the way decisions of life and death can be affected by the vicissitudes of the doctor-patient relationship (3).

Whether a physician should assist in a patient's suicide remains fundamentally a question about the framework and boundaries of clinical practice. To draw a parallel, we suggest that whether a physician should engage in a sexual relationship with a patient is less a moral or philosophical issue than one of therapeutic boundaries. The therapeutic framework that implicitly and explicitly forbids a sexual relationship allows the doctor to examine the patient's feelings with the patient. Whether a patient who seeks a sexual relationship with the doctor is "competent" is not the issue. The very presence of the prohibition against a sexual relationship makes it possible for the patient's wishes to be dealt with in a therapeutic manner. We contend that the same therapeutic framework applies to requests for physician-assisted suicide. Without a framework that prohibits the action, a doctor is not able to carefully examine the possible meanings of such a request in the total context of the patient's life, and indeed in the context of the relationship with the doctor. Such a process of therapeutic engagement is not possible within a legislative framework in which assisting suicide is a potential outcome.

Much of the debate about euthanasia and physician-assisted suicide has as its underlying assumption that doctors will always act in the interests of their patients. This assumption fails to take into account the doctor's unconscious and indeed sometimes conscious wishes for the patient to die and thereby to relieve everyone, including the doctor, of distress. The Dutch authors rightly point to the question of the violation of therapeutic boundaries and the role of countertransference in influencing how doctors behave toward suicidal patients. We suggest that countertransference is also an issue with terminally ill patients, where disgust with disease and decay may operate (4).

Legislation to enable assisted suicide has been designed to provide a safeguard, through psychiatric assessment, that protects patients from themselves (5). What these laws do not do and cannot do is protect the patient against unconscious factors in the doctor.

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References

1. Hartmann L, Meyerson A: A debate on physician-assisted suicide. *Psychiatric Services* 49:1468–1474, 1998
2. Schoevers RA, Asmus FP, Van Tilburg W: Physician-assisted suicide in psychiatry: developments in the Netherlands. *Psychiatric Services* 49:1475–1480, 1998
3. Kelly BJ, Varghese FT: Assisted suicide and euthanasia: what about the clinical issues? *Australian and New Zealand Journal of Psychiatry* 30:3–8, 1996
4. Varghese FT, Kelly BJ: Countertransference and assisted suicide, in *Countertransference Issues in Psychiatric Treatment (Review of Psychiatry, vol 18)*. Edited by Gabbard GO, Oldham JM, Riba MB. Washington, DC, American Psychiatric Press, 1999
5. Kissane DW, Street A, Nitschke P: Seven deaths in Darwin: case studies under the Rights of the Terminally III Act, Northern Territory, Australia. *Lancet* 352:1097–1102, 1998

Seven deaths in Darwin: case studies under the Rights of the Terminally Ill Act, Northern Territory, Australia

David W Kissane, Annette Street, Philip Nitschke

Summary

Background During the 9 months between July, 1996, and March, 1997, the provision of euthanasia for the terminally ill was legal in the Northern Territory of Australia. Seven patients made formal use of the Rights of the Terminally Ill (ROTI) Act;¹ four died under the Act. We report their clinical details and the decision-making process required by the Act.

Methods We taped in-depth interviews with the general practitioner who provided euthanasia. Further information was available from public texts created by patients, the media, and the coroner.

Findings All seven patients had cancer, most at advanced stages. Three were socially isolated. Symptoms of depression were common. Having met criteria of the Act, some patients deferred their decision for a time before proceeding with euthanasia. Medical opinions about the terminal nature of illness differed.

Interpretation Provision of opinions about the terminal nature of illness and the mental health of the patient, as required by the ROTI Act, created problematic gatekeeping roles for the doctors involved.

Lancet 1998; **352**: 1097-102

Introduction

On May 25, 1995, the Northern Territory Parliament in Australia passed the Rights of the Terminally Ill Act 1995 (ROTI).¹ The Act became law on July 1, 1996, making the Northern Territory the first place in the world to have legalised euthanasia.² By contrast, in the Netherlands euthanasia is sanctioned and has been openly practised since 1991, but remains technically illegal.^{3,4} In Oregon, USA, physician-assisted suicide was first enacted on Dec 8, 1994,⁵ but was deferred through appeals, until it was confirmed by a second referendum on Nov 22, 1997.

The Northern Territory ROTI Act was appealed against in the Supreme Court, but on July 24, 1996, it was ruled valid. On Sept 9, 1996, a Member of Parliament from Victoria introduced into the Commonwealth Parliament of Australia the Euthanasia Laws Bill 1996, designed to repeal the ROTI Act. This bill came into effect on March 25, 1997. In Australia the Federal Parliament can over-rule the laws of its Territories, although it cannot over-rule State laws.

The Northern Territory has a population of roughly 180 000 spread over one sixth of mainland Australia, and one third of this population is indigenous. During the period when the ROTI Act was law, four people died under the Act, on Sept 22, 1996, and Jan 2, Jan 20, and March 1, 1997. We studied the clinical decision-making process during this period of legal euthanasia. PN was the only Darwin medical practitioner who reported euthanasia deaths. He agreed to be interviewed by DWK, a consultant psychiatrist and professor of palliative medicine, and AS, a medical sociologist. We describe seven case histories of patients who sought to use the Act. Our aim was to make overt the decision-making processes involved in their care. The report is necessarily limited by the scope of medical records and the memory of PN, but we judge that it provides a useful profile. Since we have differing views about euthanasia we have not attempted a critique of the management of these patients nor a debate about euthanasia, but we simply place the case material on the public record.

The ROTI Act, 1995,^{1,2} stated that a terminally ill patient, experiencing pain, suffering, and distress to an extent deemed unacceptable, could request a medical practitioner for assistance to end his or her life. The doctor had to be satisfied on reasonable grounds that the illness was terminal and would result in the patient's death in the normal course and without application of extraordinary measures. A further requirement was that there were no medical measures acceptable to the patient which could reasonably be undertaken to effect a cure, and that any further treatment was only palliative in nature. The doctor needed to certify that the patient was of sound mind and making the decision freely, voluntarily, and after due consideration.

A second medical practitioner, a resident of the Northern Territory, was required to examine the patient

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Case	Age (years)	Sex	Marital status	Cancer diagnosis	Prominent pain	Depressive symptoms	Other clinical issues	Mode of death
1	68	F	Divorced	Caecum	No	Suicidal	Diabetes, arthritis	Suicide
2	64	M	Single	Stomach	No	No	Nausea	Natural
3	66	M	Married	Prostate	Controlled	Past history, suicidal thoughts	Anaemia, constipation	Euthanasia
4	52	F	Married	Mycosis fungoides	No	Yes, on antidepressants	Pruritus	Euthanasia
5	69	M	Single	Stomach	Controlled	No	Jaundice	Euthanasia
6	70	F	Divorced	Breast	Controlled	No	Frailty	Euthanasia
7	56	F	Single	Carcinoid	Controlled	Yes	Fistula with odour, lymphoedema	Separation

Table 1: Sociodemographic and clinical details of patients

to confirm the existence and terminal nature of the illness, and to give an opinion on prognosis to be recorded on the schedule used for certifications under the Act. The regulations required that this practitioner hold a qualification in a medical specialty related to the terminal illness, recognised by fellowship of a specialist college in Australia. If the first medical practitioner did not have special qualifications in palliative care, defined by the regulations as either 2 years' full-time practice in palliative medicine or not less than 5 years' general practice, a third doctor with such qualifications was required to give information to the patient on the availability of palliative care. A psychiatrist was also required to examine the patient and confirm that he or she was not suffering from a treatable clinical depression in respect of the illness. The Act required a period of 7 days to pass between the initial request to end life made to the first doctor and the patient's signing of an informed-consent form, witnessed by two medical practitioners. A further 48 h later, assistance to end life would be provided. A death as the result of assistance given under the Act was not taken to be unnatural, but a copy of the death certificate and relevant section of the medical record relating to the illness and death in each case had to be forwarded to the coroner. The coroner was subsequently required to report to Parliament the number of patients using the Act.

Methods

In this study, we used 18 h of in-depth audiotaped interviews with PN in Darwin. The interviews drew on his medical records and invited him to talk about decision-making processes for identified patients under his care during the period of legalised euthanasia. We also analysed documents and public texts created by patients in the form of letters and televised documentaries, documents from the coroner's court, the media, rights groups, and politicians, and the research on euthanasia and physician-assisted suicide.

The university's ethics committee approved the study, and PN gave informed consent as the key informant. Although some patients and doctors went on the public record, we have kept their identities confidential in these case reports. PN reviewed transcripts of the taped interviews for validation, and carefully reviewed the clinical material.

Results

Seven deaths were identified through PN and the coroner's records. Two patients sought euthanasia but died before the Act became law, four died under the Act, and one died after its repeal. Sociodemographic and clinical characteristics of the patients are given in table 1. Four had some symptoms of depression. Cancer was the only form of illness, and most patients presented at advanced stages, but some deferred euthanasia once satisfied that they met the requirements of the Act.

The safeguards usually considered in legislation for euthanasia are summarised in table 2. A palliative-care

nursing service was set up after the legislation became law. Three patients were socially isolated, and four had the support of spouse, children, or friends. Several treatment options remained available to patients, but their focus with PN was on euthanasia. Consensus over the terminal nature of illness proved difficult to reach in two cases.

Case 1

A divorced teacher aged 68 travelled to the Northern Territory to seek euthanasia some months before the ROTI Act was passed. She committed suicide in Darwin in September, 1995. Beside her was a letter, which said: "I have decided to end my life because I am terminally ill from cancer. I have maybe a few months to live". Her medical history included bilateral breast-reduction surgery, diabetes, moderate alcohol consumption, a suicide attempt when aged 67, and carcinoma of the caecum. She had declined surgery for the carcinoma when it was first diagnosed 6 months before her death.

In Darwin, a computed tomography scan confirmed a thickened caecum, but the patient's liver appeared normal and there was no para-aortic or pelvic lymphadenopathy. Her surgeon confirmed that biopsy at colonoscopy had diagnosed adenocarcinoma. Although the patient labelled herself as "terminally ill" when speaking to the media,⁵ PN understood her to know there was potential for surgery to be curative and that her prognosis was good.

During formal psychiatric assessment for suitability for euthanasia, the patient explained that she refused surgery for fear that it would leave her physically disabled. She was a member of the Hemlock Society. She had few friends in Darwin. She acknowledged estrangement from her son, but there was no elaboration of this, nor of her attitudes and feelings at the time of her suicide attempt 4 months previously. She did not mention her daughter, who had died quite young. She denied feeling actively suicidal, and was judged euthymic with satisfactory cognitive function.

The patient maintained her interest in dying, giving an interview on national television⁶ in which she stated she would commit suicide if the regulations necessary for the operation of the ROTI Act 1995 were not soon made law. During the evening after the interview was recorded, she became agitated and distressed, and threatened to kill herself. PN remembered this as the only occasion on which he saw her upset as she spoke about her losses and bitterness towards her son. She committed suicide 3 weeks later.

Necropsy revealed a 6.5 cm tumour at the ileocolic valve (on histology, an adenocarcinoma), with involvement of ileocolic lymph nodes but no distant spread. The patient's liver showed cirrhosis but no tumour. Blood pentobarbital concentration was 8.2 mg/L. The coroner determined the cause of death as barbiturate overdose and asphyxia.

Patient	Palliative care		Treatment options remaining	Family aware	Social isolation	Length of contact with PN (weeks)	Specialist giving second opinion	Consensus on terminal status
	Nursing	Medical						
1	No	No	Several	None (estranged)	Yes	12	None	Not terminal
2	Yes	Yes	Symptomatic	None	Yes	16	None	No
3	Yes	Yes	Radiotherapy, strontium	Spouse (children unaware)	No	25	General surgeon	Yes
4	Yes	No	Depression, symptomatic	Spouse, children	No	12	Orthopaedic surgeon	No
5	No	No	Treatment of obstruction	None (alone)	Yes	8	General surgeon	Yes
6	Yes	No	Symptomatic	Children	No	1	General surgeon	Yes
7	Yes	Yes	Depression, symptomatic	Friends	No	8	General surgeon	Yes

Table 2: Overview of protective safeguards for patients who considered euthanasia

Case 2

This patient was a single man who lived in a simple cottage in outback Australia. He had no identified relatives, but several friends were supportive to him. He had been a professional golfer, then a taxi-driver, but had ceased work owing to illness. He had surgery for gastric carcinoma 1 year before he contacted PN. The patient believed that the law on euthanasia was close to being processed, and he sought euthanasia because he just could not enjoy life: "I'm just existing, I can't see the point anymore. I've seen my time. I'm ready for the sweet long sleep".⁷ He was living on milk and yoghurt, unable to enjoy other food, and was feeling progressively weaker. His pain was well controlled.

The patient decided to drive 3000 km from his outback home to Darwin. He put his affairs in order and set off. After he arrived in Darwin, news broke of intended appeals against the legislation, and the Northern Territory's Chief Medical Officer cautioned practitioners against use of the Act until these uncertainties were settled. The general practitioner and psychiatrist who had previously arranged to examine this patient were unwilling to proceed. Regulations were then released that required the opinion of a specialist as the second certifying medical practitioner.

The patient had two hospital admissions for stabilisation of symptoms due to metastatic disease. When it became clear that he would not obtain the professional opinions necessary for euthanasia, the patient drove home again. PN had forged a friendship with this man and felt considerable responsibility for the journey the patient had made. PN travelled to the patient's home to help during the final weeks. The patient died peacefully whilst receiving good medical and nursing care at his local hospital.

Case 3

The first patient to die via legal euthanasia suffered from metastatic carcinoma of the prostate. He had worked as a carpenter, pilot, lay minister with a missionary society, and massage therapist. During middle age, he had counselling and antidepressant medication for several years. He had had two sons from his first marriage, which ended in divorce. He remarried and moved to the Northern Territory. Late in life, he became a Buddhist.

The patient had carcinoma of the prostate, which was diagnosed on inguinal-node biopsy in 1991 and managed with orchiectomy. He later underwent hernia repairs. In 1995, urinary retention was managed by transurethral resection, and this procedure was repeated 1 year later. The patient was treated with cyproterone acetate, but declined chemotherapy. During the patient's last year, anaemia aggravated breathlessness, and was only temporarily eased by blood transfusion. There was partial collapse of one lung, and pathological fractures

became a further difficulty—on one occasion ribs broke during a hug. Neither radiotherapy nor strontium was available in the Northern Territory. The patient took morphine for generalised bone pain, but was distressed by intermittent nausea, constipation, and diarrhoea, and he required catheterisation.

The memory of friends whom the patient saw die "bloody horribly" led him to fear a similar fate. He spoke of feeling sometimes so suicidal that if he had a gun, he would have used it.⁸ PN was embarrassed to witness sharp exchanges with others in which the patient would "yell and scream, intolerant as hell; you'd realise it's a last pathetic attempt at asserting himself".

The patient was cared for at home by a community palliative-care team. The patient wept frequently, and told PN that he felt it pointless to continue suffering. The patient thought his oncologist and palliative-care team minimised the severity of his predicament. In the end, they were not told he was being assessed for euthanasia, and the news of it came as a shock to those involved. A psychiatrist from another state certified that no treatable clinical depression was present.

The patient's wife was present and gave support while he received euthanasia; his sons were unaware of events until afterwards. Cremation was excluded under the ROTI Act, but was sought in the Buddhist tradition. A coroner's inquiry had to determine cause of death before permission was granted for cremation.

Case 4

This patient developed an indolent rash, mycosis fungoides, 12 years before the request for euthanasia. The rash was initially treated with psoralen and ultraviolet A, topical nitrogen mustard, and total body electron beam, with good effect. The patient had a remission for 6 months during 1994. On recurrence, she developed lymphadenopathy and nodular skin lesions, which showed that the illness had become systemic. She was treated with oral chlorambucil without improvement, then with four cycles of intensive chemotherapy. There was evidence of reduction in mass disease, but the patient complained of fatigue and her pruritus persisted, which made her reluctant to continue further chemotherapy.⁹ Her oncologist advised that the median survival of a patient with mycosis fungoides in this systemic phase was 9 months, and he said that he had no further active management to offer.

Pain was well controlled. The dominant problem was pruritus, which resulted in skin trauma, infection, eyelid oedema with closure, and persistent aural discharge. The patient's dermatologist suggested various medications including haloperidol, pimozide, fluoxetine, and naloxone. An ear, nose, and throat specialist offered guidance about ear discharge.

Psychiatric assessment was sought after the request for euthanasia. The patient said, "it's bad news, because I scratch day and night. My hands and feet blister. Yes, I want to go. I know it's the right time. I can't take any more. It's so hopeless. You want to get something to help, but you can't." She described insomnia, poor concentration, and loss of interest in her usual hobbies, tending just to lie in bed. Her latest medication included doxepin 50 mg three times daily, lorazepam 1 mg three times daily, and flunitrazepam 2 mg at night. The psychiatrist noted that the patient showed reduced reactivity to her surroundings, lowered mood, hopelessness, resignation about her future, and a desire to die. He judged her depression consistent with her medical condition, adding that side-effects of her antidepressant medication, doxepin, may limit further increase in dose.

When the patient first travelled to Darwin, PN looked for a specialist who would give a second medical opinion. Two surgeons agreed to see her and then withdrew; one physician assessed her and declined to certify that she was terminally ill. At this politically controversial time, the patient made a public appeal for help, which was broadcast on national television. After this programme, an orthopaedic surgeon agreed to see her and certified that the ROTI Act had been complied with. Having obtained the necessary signatures, the patient went home to spend Christmas with her family, before returning to Darwin, accompanied by her husband and one child. She underwent euthanasia on Jan 2, 1997.

Case 5

This elderly man lived alone in the Northern Territory, had never married, had migrated from England, and had no relatives living in Australia. He had had a partial gastric resection for carcinoma of the stomach. He sought euthanasia because he saw no point in going on with pain and suffering when he was advised that he would not recover.

Computed tomography 4 months before euthanasia revealed diffuse smooth thickening of the peritoneum throughout the abdomen, associated with a moderate amount of free ascites. The liver was of normal size and uniform density and the gallbladder was absent. There was mild dilatation of intrahepatic and extrahepatic biliary ducts without evidence of a discrete obstructing mass. The residual gastric remnant was distended. There was no evidence of abnormal abdominal or pelvic lymphadenopathy. There was partial obstruction of the right kidney, with its ureter dilated as far as the common iliac vessels. There was no discrete obstruction mass, but there was evidence of adjacent peritoneal disease. The left kidney was normal.

About 2 months after the scan, the patient was staying in hospital, and telephoned PN to discuss euthanasia. The patient's surgeon confirmed the prognosis as hopeless and agreed to certify this. However, the patient sought time to think about euthanasia, and invited PN back twice over the next 2 months. The patient queried what would occur, and given his indecisiveness, PN encouraged him to wait. Finally, the patient signed the consent and selected a date for euthanasia.

The patient was assessed by a psychiatrist on the day on which euthanasia was planned—this timing was not excluded by the Act. The patient was emaciated, clinically jaundiced, and so weak that he needed a

wheelchair for transport. Nevertheless, he was alert and able to converse, giving a clear account of his illness and wishes. He denied being depressed. He complained of mild background pain incompletely relieved by medication. He was constantly nauseated, vomited intermittently, and kept down only liquids. PN recalled that on this occasion the psychiatrist phoned within 20 min, saying that this case was straightforward. The patient was taken back to his own home, which had been shut up for some weeks. PN recalls his sadness over the man's loneliness and isolation as he administered euthanasia.

Case 6

This divorced woman flew to Darwin from another part of Australia, accompanied by her children. She had advanced metastatic carcinoma of the breast and had had primary surgery in 1994. The patient's sister had died recently from breast cancer, and she was distressed at having witnessed this death, particularly the indignity of double incontinence. The patient feared she would die in a similar manner. She was also concerned about being a burden to her children, although her daughters were trained nurses.

PN was first contacted by one of the patient's sons, who gave a coherent account of his mother's disease. She had been well until mid-1996, when her legs began to swell and retroperitoneal lymphatic involvement was diagnosed. Despite chemotherapy, the disease progressed, and regular analgesia was needed for abdominal pain. The patient moved to live with a daughter, but became more frail and lost strength over 6 months of active treatment, and eventually became bedridden. Although receiving palliative care, she said, "I don't like being like this; I want to die". She discussed euthanasia with her children, who agreed and organised her flight to Darwin.

In Darwin, the patient was judged by a general surgeon to have extensive metastatic disease, for which there was "no further conventional treatment that would alter her prognosis, which was that of death in the near future". A psychiatrist certified that she was not clinically depressed and that she had full comprehension of her situation. A week after the patient arrived in Darwin, she was moved from hospital to a hotel apartment, where she said goodbye to her children, speaking to each in turn. She underwent euthanasia surrounded by her family.

Case 7

This 56-year-old woman lived alone. She first developed a carcinoid tumour of her small bowel in 1977, presenting with intussusception. The mesenteric lymph nodes were involved at that time. She remained well until abdominal discomfort developed in 1991, when recurrent carcinoid was found at laparotomy. She underwent wedge excision of hepatic metastases, debulking of pelvic tumour, and bilateral oophorectomy. Inguinal lymph nodes were involved, leading to lymphoedema. The patient retired from her nursing job at that stage.

In 1996, the patient developed a subacute bowel obstruction, and needed ileocolic bypass and loop sigmoid colostomy. There was evidence of diffuse pelvic tumour and malignant ascites. She made a slow recovery, complicated by methicillin-resistant *Staphylococcus aureus* infection of a wound-drain site that eventually became a

permanent fistula. She was troubled by odour from the fistula, and thereafter limited her social activities. Discharge from her fistula was lessened with octreotide.

Over subsequent months, the patient's bilateral lymphoedema worsened, her sleep was disturbed, and she started to lose weight. She had intractable pain in her right groin, extending around to her back. The pain was treated with subcutaneous morphine, but the patient became more and more unhappy. She had been an avid reader, but stopped owing to poor concentration. She withdrew further, and stopped letter-writing. No longer able to leave the house, the patient needed a friend to sleep at her house in case she needed assistance overnight. By February, 1997, having thought increasingly about euthanasia, the patient completed the necessary documentation, but did not yet want to die. She continued with palliative care and support from a team of nursing friends beyond the repeal of the ROTI legislation in March, 1997.

However, by mid-April, 1997, the patient's general practitioner described her as mentally and physically exhausted, more distressed than ever before, and now actively suicidal. The patient sat with fixed gaze and drooping eyelids. Given that the ROTI Act was no longer available, the patient agreed to an intravenous infusion of morphine and midazolam as terminal sedation. At first, the infusion contained morphine 1440 mg plus midazolam 15 mg over 24 h, and the doses increased to morphine 4800 mg plus midazolam 200 mg plus ketamine 400 mg per 24 h over the next 3 days, supplemented by boluses of phenobarbital and chlorpromazine when the patient was restless. The patient's management generated much discussion, since it was documented on national television. At necropsy, cause of death was given as bronchopneumonia, carcinomatosis, and mixed drug overdose; the coroner decided to take no further action.

Discussion

In their review of euthanasia in the Netherlands in 1995, van der Maas and colleagues³ estimated that some 2.3% of deaths resulted from euthanasia, 0.7% without the patient's explicit consent. Moreover, van der Wal and colleagues⁴ concluded that only 41% of all cases of euthanasia or physician-assisted suicide were reported. Euthanasia is broadly accepted within Dutch society. By contrast, a survey in the USA¹⁰ that explored attitudes and experiences of oncology patients found that those with depression were more likely than those without depression to request assistance in committing suicide. These findings matched those of other studies in Australia,¹¹⁻¹³ Canada,^{14,15} and the USA,¹⁶ which have all found an association between depressive disorder and the desire to die. The citizens of Oregon reconfirmed by referendum their desire to be able to undergo physician-assisted suicide if terminally ill.

The limitations of our study include the small sample, from which it is difficult to make generalisations, and uncertainties about clinical details in some cases. Thus, when questioned about options like stenting for obstructive jaundice or the management of bowel obstruction, PN acknowledged limited experience, not having been involved in care for the dying before becoming involved with the ROTI Act. Despite these limitations, the narrative that emerged is rich in describing those patients who sought euthanasia, and it

provides helpful insight into the utility of regulations on euthanasia.

The ROTI Act defined a terminal state as one leading to death in the "normal course" of illness progression. The first patient would not have met these requirements of the Act, because her cancer had not yet reached the stage at which it would have resulted in death; she was the type of patient who seeks euthanasia without a terminal or hopeless situation. The fourth case showed the Act's lack of ability to deal with differences of opinion: one oncologist gave the patient's prognosis as 9 months, but a dermatologist and a local oncologist judged that she was not terminally ill. Other practitioners declined to give opinions. In the end, an orthopaedic surgeon certified that the ROTI provisions for terminal illness had been complied with.

Medical practitioners working with the ROTI Act had to exercise clinical judgment about the nature and process of an illness, its previous and current management, and any further potentially worthwhile treatment. The decision-making process involved review of the accuracy of diagnosis and the suitability of treatment, with exclusion of confounding factors. This could be described as a gatekeeping function, in which the vulnerable are protected through the wise application of the law. The potential length of future life of a patient with cancer can be very difficult to judge accurately, and differences of expert opinion were evident in two of these cases.

The ROTI Act specifically required a psychiatrist to confirm that patients were not suffering from a treatable clinical depression. Confirmation was not easy since patients perceived such a mandatory assessment as a hurdle to be overcome. PN 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? In case 1, there was important background detail about the death of one child and alienation from another, which was withheld during the psychiatric assessment. These experiences may have placed the patient in a lonely, grieving, demoralised position: an unrecognised depression may have led to suicide. Four of the seven cases had symptoms of depression, including reduced reactivity, lowered mood, hopelessness, and suicidal thoughts. Case 4 was receiving treatment for depression, but no consideration was given to the efficacy of dose, change of medication, or psychotherapeutic management. PN judged this patient as unlikely to respond to further treatment. Nonetheless, continued psychiatric care appeared warranted—a psychiatrist can have an active therapeutic role in ameliorating suffering rather than being used only as a gatekeeper to euthanasia. Ganzini and colleagues¹⁷ showed that only 6% of psychiatrists in Oregon, USA, thought that they could be a competent gatekeeper after a single assessment of a patient. This finding illustrates the difficulty of legislation of this sort—there is an important role for psychiatry in oncology and palliative care to ensure that depression is actively treated, but a gatekeeping role may be flawed if seen as adversarial by patients and viewed as blocking successful treatment, rather than being one part of proper multidisciplinary care.¹⁸

The ROTI Act was designed to encourage patients to make active and early use of palliative care, and to be

fully informed about care options. However, the political debate surrounding the Act tended to cast practitioners of palliative care as opponents of the euthanasia campaigners, potentially to the detriment of patients' care. Furthermore, palliative-care facilities were underdeveloped in the Northern Territory, and the patients in our study needed palliative care. Burt¹⁹ suggests that the US Supreme Court identifies a constitutional right to palliative care, especially for the alleviation of pain and other physical symptoms, for people facing death.

Pain was not a prominent clinical issue in our study. Fatigue, frailty, depression, and other symptoms contributed more to the suffering of patients. There is a need to respond creatively to social isolation, and to treat actively all symptoms with early and skilled palliative care. Education in providing palliative care is a priority for many communities, including the Northern Territory.

Our case material shows that the assessment of depression is difficult in the terminally ill, and accurate prediction of prognosis is subject to disagreement. There are clear limitations of the gatekeeping roles of the medical specialist and psychiatrist in the ROTI legislation. However, we have deliberately avoided being drawn into the debate about euthanasia and physician-assisted suicide.

References

- 1 Rights of the Terminally Ill Act 1995, Northern Territory of Australia. Darwin: Government Printer, 1995.
- 2 Rights of the Terminally Ill Regulations 1996, Northern Territory of Australia. Darwin: Government Printer, 1996.
- 3 van der Maas PJ, van der Wal G, Haverkate I, et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. *N Engl J Med* 1996; 335: 1699-705.
- 4 van der Wal G, van der Maas PJ, Bosma JM, et al. Evaluation of the notification procedure for physician-assisted death in the Netherlands. *N Engl J Med* 1996; 335: 1706-11.
- 5 McCarthy M. Oregon's euthanasia law. *Lancet* 1994; 344: 1494-95.
- 6 Wilkinson P. Euthanasia. Sydney: Sixty Minutes Television Production, Nine Network, 1995.
- 7 McLaughlin M. The road to nowhere. Sydney: Four Corners Television Production, Australian Broadcasting Commission, 1996.
- 8 Dent RB. Open letter to federal parliamentarians. Sept 21, 1996. Melbourne: The Age Online; 1997.
- 9 Mills J. Letter written a day before death. Jan 1, 1997. Melbourne: The Age Online, 1997.
- 10 Emanuel EJ, Fairclough DL, Daniels ER, Clarridge BR. Euthanasia and physician-assisted suicide: attitudes and experiences of oncology patients, oncologists, and the public. *Lancet* 1996; 347: 1805-10.
- 11 Owen C, Tennant C, Levi J, Jones M. Suicide and euthanasia: patient attitudes in the context of cancer. *Psychooncology* 1992; 1: 79-88.
- 12 Owen C, Tennant C, Levi J, Jones M. Cancer patients' attitudes to final events in life: wish for death, attitudes to cessation of treatment, suicide and euthanasia. *Psychooncology* 1994; 3: 1-9.
- 13 Hooper SC, Vaughan KJ, Tennant CC, Perz JM. Major depression and refusal of life-sustaining medical treatment in the elderly. *Med J Aust* 1996; 165: 416-19.
- 14 Brown JH, Henteleff P, Barakat S, Rowe CJ. Is it normal for terminally ill patients to desire death? *Am J Psychiatry* 1986; 143: 208-11.
- 15 Chochinov HM, Wilson KG, Enns M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152: 1185-91.
- 16 Breitbart W, Rosenfeld BD, Passik SD. Interest in physician-assisted suicide among ambulatory HIV-infected patients. *Am J Psychiatry* 1996; 153: 238-42.
- 17 Ganzini L, Fenn DS, Lee MA, et al. Attitudes of Oregon psychiatrists toward physician-assisted suicide. *Am J Psychiatry* 1996; 153: 1469-75.
- 18 Ryan C, Kelly B, Samuels A, et al. Australian psychiatry and euthanasia. *Aust Psychiatr* 1996; 4: 307-08.
- 19 Burt RA. The Supreme Court speaks: not assisted suicide but a constitutional right to palliative care. *N Engl J Med* 1997; 337: 1234-36.