

The Northern Territory Rights of the Terminally Ill Act 1995 and the Euthanasia Laws Act 1997 What really happened?

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Professor Colleen Cartwright
Principal Director, Cartwright Consulting Aust
Emeritus Professor, Southern Cross University
colleen.cartwright@scu.edu.au

Background - 1

Uni of Qld Research: main team members Profs Steinberg, Williams, Najman, Parker, Cartwright.

Team made commitment to stay neutral on whether or not euthanasia should be legalised in Australia (regardless of our personal positions) so our research would have credibility; this proved to be so.

Advisory Committee established; included members both pro- and anti-euthanasia; doctors, nurses, a Catholic nun, an ethicist, community members. All survey questions in all studies had to be agreed by all Advisory Committee members to ensure no bias.

Euthanasia was defined as “Taking active steps to end the life of a person, at that person’s request, for what s/he sees as being in her/his best interests”

Background - 2

3 studies conducted in Qld:

1. 1995: Doctors, Nurses and Community Members (large sample – 1300 health professionals, 1100 community members)
2. 1996: GPs and patients they had seen in previous 12 months
3. 2001: Doctors, Nurses, Social Workers and Community Members (the latter stratified by age group)

Covered a range of issues relating to end-of-life care, including Advance Care Planning, pain management, palliative care, physician-assisted suicide and euthanasia.

(NOTE: NT study conducted 1997 – reported separately).

Community Concerns in Terminal Illness: Rank Order

FACTORS	Q1	Q2	NT
Loss of Mental Faculties	1	1	1
Loss of Control	2	2	2
Loss of Independence	*	3	3
Burden on Family	*	4	4
Loss of Dignity	4	5	5
Leaving Loved Ones	5	*	6
Protracted Dying	*	*	7
Extreme /Physical Pain	3	6	8
Death Itself	9	9	10/10

Confusion About what is/is not Euthanasia

- A major problem is confusion over what is, or is not, euthanasia. This leads to:
 - Inadequate pain management
 - Inappropriate use of medical technology
 - Fear among health professionals of legal consequences of care provision
 - Poor doctor-patient communication
 - Disillusioned patients/families/carers

Common Beliefs

- Some commonly held beliefs are that euthanasia includes:
 - (a) giving increasing amounts of needed pain relief which may also have the effect of shortening the person's life; or
 - (b) respecting a patient's right to refuse further treatment; or
 - (c) withholding or withdrawing life support systems that have ceased to be effective or that will provide no real benefit to the patient

None of these is euthanasia

Definitions of Euthanasia

- The World Medical Association defines euthanasia as the deliberate ending of a person's life at his or her request, using drugs to accelerate death.
- Definition used in our studies in Australia & Europe
 - Euthanasia is a deliberate act intended to cause the death of the patient, at that patient's request, for what he or she sees as being in his/her best interests (i.e. Active Voluntary Euthanasia – AVE).

Giving Pain Relief Which May Also Shorten the Patient's Life

- Often referred to as "the doctrine of double effect" - primary intention is to relieve pain, secondary, unintentional effect may be the hastening of the person's death.
- Accepted by most religious and medical groups, including those who strongly oppose euthanasia.
- Not giving adequate pain treatment when needed may shorten life: patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated.

Respecting a Patient's Right to Refuse Treatment

- This is a legal and moral right possessed by every competent person, under both common law and, in some States/ Territories, under statute law relating to assault; also by non-competent patient by ACD or legally-authorized substitute decision-maker.

Withholding/Withdrawing Futile Life-Supports Systems

- Used to be called "passive euthanasia"; general agreement that that term is unhelpful - it can lead to the inappropriate continued use of invasive technology.
- Often it is not prolonging life, it is merely prolonging the dying process.
- Removal of futile treatment is good medical practice. However, no definition of futility in law; generally agreed, when burden outweighs benefits – but “burden” and “benefit” should be from patient’s viewpoint.

Some Findings from Qld Studies 1 & 2

- Responses to the following questions:
 - Should a doctor switch off a life-support machine, if asked to do so by a competent patient? (% Yes)
HPs/GPs – 65%/56%; Community/Patients – both 72%
 - Should a doctor or nurse give extra morphine if requested by terminally ill patient? (% Yes)
HPs/GPs – 95%/94% doctor should; 91%/80% nurse should
Community/Patients – (1) 85% combined dr/nurse should
(2): 91% doctor should; 74% nurse should
 - Should the law be changed to allow active voluntary euthanasia for terminally ill people who no longer wish to live? (% Yes)
HPs/GPs – (1) 43%/33%; Community/Patients – both 65%

The NT Rights of the Terminally Ill (RoTI) Act (1995): Time-line

22 Feb 1995: RoTI Bill introduced into NT Parliament by Chief Minister, Marshall Perron; immediately after first reading, member Bell moved that Bill not be read a 2nd time – motion defeated 12-13; moved by Marshall Perron that Bill be read a 2nd time – motion passed 13-12.

5 member bi-partisan Parliamentary Select Committee set up to examine the Bill; called for submissions from the community;

1,126 written submissions were received; 814 (72%) were in favour of euthanasia or right of choice: 300 (27%) were opposed to euthanasia or the Bill itself;

255 (23%) were from NT residents – 122 in favour: 123 against the Bill (i.e., almost equally for and against the Bill)

Submissions from outside NT, pro or anti the Bill:

State/Territory	Pro (%)	Anti (%)
ACT	24 (92.3%)	2 (7.7%)
NSW	513 (95.5%)	24 (4.5%)
QLD	21 (50%)	21 (50%)
SA	3 (2.3%)	10 (97.7%)
VICTORIA	10 (8.3%)	110 (91.7%)
WA	115 (95.8%)	5 (4.2%)
UK		2 (100%)
US		2 (100%)
TOTAL: 862	686 (79.6%)	176 (20.4%)

RoTI Act Timeline (cont.)

- **24 May 1995:** Marshall Perron resigned, immediately before the debate and vote for 3rd and final reading of Bill;
- All 25 Parliamentarians took part in the 14-hour debate. There were 49 amendments and a conscience vote which split both parties;
- **25 May 1995** – 3am: Motion to allow 3rd and final reading, passed 15-10.
- **16 June 1995:** NT Administrator, Austin Asche, assented to the Bill, with regulations added. (RTI Act 1995, No 12 1995, for commencement **1/7/1996**)
- (Commencement delayed to that date to allow NT Government to upgrade palliative care services and make regulations covering issues such as drugs to be used to end life, and to allow for implementation of education program).

RoTI Act Timeline (cont.)

- **23 Nov 1995:** Steve Hatton, then NT Attorney General, presented an amendment to the RTI Act; this went through the first and 2nd readings and then into debate; debate continued until **20 Feb 1996**, when the RTI Amendment Acct was passed. One amendment increased the requirement for 3 doctors to be involved, one of whom must be psychiatrist.
- **20 Feb 1996;** (1) amendment proposed to insert a “sunset clause” to make RTI Act non-operational after July 1999: defeated. (2) Mr Bell called for suspension of Standing Orders to allow him to present the Respect for Human Life Bill, which would repeal the RTI Act; request denied.
- **20 March 1996:** RTI Amendment Act assented to by Austin Asche.
- **15 May 1996:** 2 Bills to repeal RTI Act presented by Mr Bell; (1) Respect for Human Life Bill; (2) Care of the Dying Consultation Bill. Both passed 1st & 2nd reading; debate adjourned; resumed **21 August 1996;** (1) defeated 14-11; (2) “debate negatived” (as per Hansard)

RoTI Act Timeline (cont.)

- **June 1996:** 2 challenges made to RTI Act; (1) to Full Bench of NT Supreme Court, by Coalition Against Voluntary Euthanasia, to declare Act unconstitutional; (2) Federal House of Reps backbencher, Kevin Andrews, proposed Private member's Bill to overturn the RTI Act.
- **June 1996:** Prime Minister Howard supports **national action** against euthanasia.
- **1 July 1996:** (1) **RTI Act enacted**; (2) NT Supreme Court challenge defeated; (3) Max Bell (t/ill ca patient) declares desire to use the law; drives his taxi from Broken Hill to Darwin.
- **24 July 1996:** NT Govt upheld the constitutionality of RTI ACT
- **2 Aug 1996:** Max Bell dies in NSW, after Dr Nitschke could not find 2 other doctors in NT to confirm his diagnosis and capacity.
- **21 Aug 1996:** Eric Poole presented Bill to amend RTI Act to not allow euthanasia to be carried out in public hospitals or health clinics; Bill is read twice, then defeated 15-10.

RoTI Act Timeline (cont.)

- **9 Sept 1996:** Kevin Andrews introduces the Euthanasia Laws Bill into Federal Parliament House of Reps, aimed at overturning RTI Act. 1st reading of Bill.
- **17 Sept 1996:** Bulletin-Morgan national poll asks: “Should a hopelessly ill patient who asks for a lethal injection be given one?” 70% of respondents say Yes
- **17 Sept 1996:** Reported in Bulletin: NT Country-Liberal member, Nick Dondas says, if Andrews Bill succeeds it will “breach over 150 years of constitutional history, practice and convention.”
- **22 Sept 1996:** 1st person to use RTI Act, Bob Dent, used Dr Phillip Nitschke’s syringe-driver and died; no NT psychiatrist would sign document confirming that Mr Dent was not suffering from a treatable depression – Sydney psychiatrist attended.
- **28 Oct 1996:** Euthanasia Laws Bill read for second time;
- **10 Dec 1996:** Bill read for 3rd time – passed 88-35; Sent to Senate: Senate Legal & Constitutional Committee established Enquiry

Our NT Study

- NT Director of Palliative Care sent a message asking my team to repeat Qld studies in NT. (Research conducted while RTI Act was still in operation)
- Linked with 2 researchers in Social Science Dept at Darwin Uni (as it was then): Prof Bill Tyler and Dr (now Prof) Gary Robinson
- Survey sent to:
 - all GPs and other medical practitioners (except pathologists and radiologists) currently registered in NT (n=343); 174 responded (51%)
 - Random sample of 415 nurses currently registered in NT ; 243 responded (59%)
 - Random sample from the NT Electoral Roll, stratified by age group, of 1070 community members from (1) Darwin/Darwin rural area; and (2) Alice Springs/ Katherine; 535 responded (50%).

Some Findings from NT Study

- Responses to the following questions:
 - Should a doctor switch off a life-support machine, if asked to do so by a competent patient? (% Yes)
HPs – 58%; Community members – 71%
 - Should a doctor or nurse give extra morphine if requested by terminally ill patient? (% Yes)
HPs – 95% doctor should; 88% nurse should
Community members – 87% doctor should; 71% nurse should

Study participants were then asked: “To what extent do you approve of the new NT law allowing physician-assisted suicide or euthanasia for terminally ill people?” (5-point scale, *Strongly Approve to Strongly Disapprove*)

LEVELS OF APPROVAL FOR NT *RIGHTS OF THE TERMINALLY ILL ACT*

GROUP	SA/A	NEITHER	D/SD
	%	%	%
Medical Practitioners	35	17	48
Nurses	66	14	20
Community Members	75	7	18

**SA = Strongly Approve, A = Approve;
D = Disapprove, SD = Strongly Disapprove**

Qualitative Data from NT Study

- Written responses to question on approval of the RTI law found that % approving or disapproving did not necessarily reflect approval/disapproval of euthanasia, only of the law: e.g.,
- Two doctors who *strongly disapproved* of the new law:
 - (1) “I’m not opposed to euthanasia but I don’t think we should hand such a can of worms to lawyers and bureaucrats”;
 - (2) “I’ve been helping my patients with this for years; we don’t need a law about it”.
- Two community members who *strongly approved* of the law:
 - (1) “Tell the Commonwealth to keep out of our business”
 - (2) “John Howard needs brain surgery”.

The Euthanasia Laws Act (1997)

- Kevin Andrews Private Member's Bill sought to use the Constitutional right of the Commonwealth Government to overturn RTI Act and prevent any other Territory introducing similar legislation. (NB: Commonwealth could not overturn legislation passed by a State).
- Commission of Enquiry called for submissions re: Andrew's Bill
- Kevin Andrews took a team of people around the NT, arguing against euthanasia. Evidence of misinformation and "fear-mongering".
- Churches throughout Australia asked parishioners to collect form letters from presbyteries and use as basis for submissions against euthanasia
- **12, 578** written submissions received. Commission said that **93%** were in favour of overturning the RTI ACT (cf our population surveys).
- Analysis for today's presentation; **first 6,474** submissions checked - detailed reading of first 500; remainder scanned for new issues and/or whether for or against euthanasia.



QUANTITATIVE SUMMARY OF ANALYSIS:

TOTAL SUBMISSIONS ANALYSED = 6,474

INDIVIDUALS = 6,327

Total Signatures	In favour of Voluntary Euthanasia	Against Voluntary Euthanasia	Illegible, Not Clear or Not Stated	Neutral or Anti Both RTI Act & EU Laws Bill	States' Rights* Only
7,353	693 (9.4%)	6,611 (90%)	32 (<1%)	6 (<1%)	(<1%)

QUANTITATIVE SUMMARY OF ANALYSIS:

TOTAL ORGANISATIONS = 147

Total Organisations	In favour of Voluntary Euthanasia	Against Voluntary Euthanasia	Illegible, Not Clear or Not Stated	Neutral or Anti Both RTI Act & EU Laws Bill	States' Rights* Only
147*	19 (13%)	116 (79%)	3 (2.0%)	4 (2.7%)	5 (3.4%)

Qualitative Data from Individual Submissions - 1

- Evidence of great confusion in submissions, about what EU Laws Bill was and about the fact that euthanasia was already legal in NT; many similar to, e.g.,
 - “Please do not legalise euthanasia”
 - “The passing of this (UE Laws) Bill is against the sanctity of human life”, then argues against euthanasia, adding “God will decide when our time is up.”
 - “I disagree very strongly with this legislation”, then argues against euthanasia (as above).
- Very strong evidence that people were provided with wording, e.g., majority of Anti-euthanasia submissions start with one of following:
 - “I write to express my strong opposition to euthanasia”
 - “I strongly object to euthanasia”
 - “I am strongly opposed to the NT Act which legalises euthanasia”.

Qualitative Data from Individual Submissions

- Hundreds of Form letters, still with instructions attached, some from Churches, some from the Euthanasia NO campaign, 1 from pro-euthanasia group. Wording identical on each group of letters.
- References to God or being Christian were in many Anti-euthanasia submissions;, e.g.,
 - “Only God can decide when I die”;
 - “As a committed Christian ... (anti eu)”;
 - “I believe in the Commandment, “Thou shalt not kill”
- In some submissions the writer says that their church asked them to write a submission against euthanasia but they could not comply as they were not opposed to euthanasia. One said : “Every person who is a member of a church does not feel this way (i.e., opposed to euthanasia), and our spokespersons in the end are only voicing their own opinions.”
- It is legitimate in a democracy to wage a strong campaign to convince people to vote the way you want them to but it is morally problematic to spread lies and misinformation to do so. (Next slide)

Qualitative Data from Individual Submissions

- MISINFORMATION: several submissions, including one with a form letter provided to the submitter, refer to “what the Nazis did”. Another starts “In the 1930’s & 40’s Adolf Hitler practiced euthanasia ...”

(Note: What the Nazis did was murder and genocide, not euthanasia, i.e. a “good or peaceful death” [original Greek meaning], no matter what the Nazis called what they did).

- Other false claims included: “A survey published in the *New Scientist* found that 60% of people in the Netherlands were euthanased (sic) without their permission. Anecdotal evidence from friends there is that people over 70 put off going to hospital because they fear they will not come out.” (The factual evidence, gathered by rigorous research, does not support either of these contentions).
- Some were very confused – but in some cases, amusing, e.g.,
- “if euthanasia is legalised “our anthem ‘Land of Hope and Glory’ could never be sung again.”
- “Do not legalise abortion ... elderly people are frightened of falling ill”.

Qualitative Data from Individual Submissions

- Others expressed fear (many from misinformation in Form letters):
 - “Euthanasia is a contentious issue and I believe it will never be safe to live in a society of legalised abortion” (sic)
 - “Like many other elderly people, I am afraid that if euthanasia is legalised I might be put to death at the whim of some ‘do gooder’ doctor.”
- Many submissions claimed that people who support euthanasia do so because they believe it means turning off “life support machines”.
- Or: opinion polls are misleading and people don’t understand what euthanasia really is.
- OTHER FEARS:
- Impact on quality of health care for old/disadvantaged people;
- Euthanasia is cheaper than good palliative care;
- Open to abuse; can never be safe; people will be pressured into asking for it.

Qualitative Data from Individual Submissions

- Many submissions from **Aboriginal people**. Almost all were typed, some signed with X; they say very similar things against euthanasia, which suggests that the wording may have been suggested to them, e.g.:
 - I do not want injections. Me and my children. I will die at the right time with who creates. It is the law
 - I do not like the injection. Me and my family, my wife. I still want to die at the right time but that is all
 - I am totally against the law. I am not for it. ... I totally reject it. So that our people will not die in hospital.

(Note: a respondent to our NT survey wrote: “All I hear is that Aboriginal people are opposed to this legislation (i.e., RoTI Act). Well I’m Aboriginal and I’m not opposed to it.”)

- Submission from NT Anti-Discrimination Commissioner recommends providing educational videos –**IN LANGUAGE** (original emphasis) to dispel fear and misunderstanding in Aboriginal Communities.

RoTI Act Timeline (cont.)

- **2 Jan 1997:** Mrs Janet Mills used the syringe-driver, becomes 2nd person to die under the RTI Act. (Mrs Mills had to “go public” before a specialist agreed to sign her documentation; again, Sydney psychiatrist)
- **20 Jan 1997:** 69-year-old man with stomach cancer, prognosis of a few weeks to live, used the syringe-driver. (First time all 3 doctors from NT)
- **24-25 Jan 1997:** Senate Hearings in Darwin
- **13-14 Feb 1997:** Senate Hearings in Canberra
- **1 March 1997:** 72-year-old woman from Sydney becomes 4th person to die under the RTI Act
- **6 March 1997:** Senate Committee reports on Enquiry but does not make recommendations re: conscience vote
- **20 March 1997:** 2nd reading of *Euthanasia Laws Bill* passed by Senate, followed by debate;
- **25 March 1997:** Senate votes to strike down *RTI Act*. Governor-Gen was asked for special dispensation for 2 t/ill patient to use law: refused.

(POSTSCRIPT)

- It had been reported to me that some Voluntary Euthanasia Societies had taken up petitions in support of the NT RTI Act, and of euthanasia itself, but that each petition was counted as 1 submission.
- I found no evidence of that in the 6,474 submissions I reviewed, i.e., 59/109 volumes of submissions.
- I had one more “quick browse” through the remaining 50 volumes – and, in one of the last 3, I found:
 - 1/ A submission from the Qld Sunshine Coast VES in support of euthanasia and the RTI Act, included a petition with 2,485 signatures – that was counted as 1 submission in favour of euthanasia and the RTI Act; and
 - 2/ A submission from a Chinese Presbyterian Church with 228 form letters attached – brief intro in English, main part in Chinese – each one signed. That was counted as 229 submission against euthanasia and the RTI Act.