# End-of-Life Options: The Key Issues

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# Context

- Better living conditions/health care have led to increased longevity – this is a success story, and it has rightly been celebrated as such.
- In addition, rapid technological development has allowed people who would have previously died to be kept alive for long periods of time, often through the use of such things as ventilators and PEG tubes.
- *But*
- These successes have led to practical, legal & ethical issues, in particular around end-of-life care and extending the dying process, including for the increasing numbers of people with dementia.

# Carers' Stories

- (Husband) Close to the end of his wife's life, "because the cancer was attacking the bone and she had bad pain in her hip, they put a pin in. And …it was a terrible mess…It just added to her pain. And they gave her more chemo as well…and they took numerous X-rays, 3 or 4 a day".

- (Wife) "First of all he was stubborn when he was in hospital; he wouldn't eat - he was just starving himself. They couldn't get him to eat … so they had to force-feed him. They put a tube down his nose and then they had to tie him in the bed, because he kept pulling it out. He just didn't want it".

  (It is an assault to continue to treat a competent patient who has refused treatment, even to save that person's life).

# Community Concerns in Terminal Illness: Rank Order for 3 Studies

| FACTORS | Study 1 | Study 2 | Study 3 |
|---|---|---|---|
| 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[1] /Physical Pain[2,3] | 3 | 6 | 8 |
| Death Itself | 9 | 9 | 10/10 |

# Advance Care Planning Helps to Address Fears & Concerns

- Health/Personal Care Mechanisms:
  - Appoint an Enduring Guardian to make your decisions in a case of future time of loss of capacity (usually a trusted relative or friend)
  - Write wishes in Advance Care Directive
  - Person Responsible provision, **if no-one has been appointed by the patient**

# Enduring Guardian -1

- A competent person over 18 can appoint an Enduring Guardian (EG) to make decisions about medical/dental treatment and/or lifestyle decisions on their behalf, in case they lose the capacity to make own decisions.
- EG: must be at least 18 years old; is usually a trusted relative or friend. (Appoint someone “tough enough” to stand up for your wishes and legal rights)
- EG cannot be a person who, at the time of appointment:
  - Provides medical treatment or care to the person on a professional basis; or
  - Provides accommodation or support services for daily living on a professional basis; or
  - Is a relative of one of the above.

# Enduring Guardian - 2

- A person can appoint more than 1 EG.
  - If more than 1 EG is appointed, the principal needs to state how they are to make their decisions (jointly, severally).
- EG must agree to the appointment, should understand the principal's wishes and be prepared to carry them out.
  - Appointment must be in writing, in approved form.
  - Form must be signed by principal and witnessed by a solicitor, barrister or JP. (Attorney must sign and signatures have to be witnessed – not necessarily on the same day).

# Advance Care Directives

- An Advance Care Directive
  - is a written legally-binding document, which allows a person to make their wishes for future health care known
  - extends the current legal right of a competent person to refuse treatment to a future time when they may not be competent
  - is NOT a form of euthanasia, as it only allows actions which a person could legally consent to for themselves if they were competent to speak
- As with EG, it only comes into effect when the person making it loses decision-making capacity.
- All states/Territories in Australia have statute law for ACDs except NSW & Tas; in NSW/Tas, legally binding under common law (3 cases in NSW)

# Recent study: Scenario (abbreviated)

- 55 year-old woman; diagnosed with MND 6/12 ago.

Taken unconscious to hospital after a car accident; now stable but still unconscious. Decisions needed about her medical treatment.

Husband listed as next-of-kin on previous hospital records but they have been separated for many years and do not see each other often.

For the last 5 years, the patient has lived with her same-sex partner.

The patient and her husband have two adult children, a son and a daughter.

Her son has Enduring Power of Attorney for her.

Her daughter has recently taken 3 months leave to care for her mother full-time.

- Respondents were asked: If all 4 were present at the patient's bedside, who would be legally entitled to consent to her medical treatment?

# Scenario - Results

| STATE | Husband | Son | Daughter | Partner | Don't Know | Correct |
|---|---|---|---|---|---|---|
| **Qld** | 18% | 15% | 12% | **31%** | 24% | **Partner** |
| **NSW** | 8% | **52%*** | 8% | **22%** | 10% | **Partner** |
| **Vic** | 21% | 7% | 13% | **36%** | 23% | **Partner** |

- 29% overall gave correct answer; lowest correct response was in NSW, where 52% of medical specialists said "son" who had Enduring Power of Attorney
- In NSW, Enduring Power of Attorney applies only to decisions about money and property and **does not give that person authority to make healthcare decisions**

# What if there is no ACD or EG?

- There is a specified "order of authority" in the legislation for who can make health care decisions, including refusal of treatment (called Person Responsible in NSW): that is the first readily available of:
  - A spouse (including de facto or same sex partner, provided the relationship is close and continuing).
  - A (non-professional) carer*.
  - A close relative or friend of the patient.

(Note: **Not** Next-of-Kin and may not be the person the patient would have chosen to make their decisions).

* For a person in a RACF, "carer" is not a staff member at the facility. Usually it would be whoever was the carer before the person went to the facility.

## **When Does a Person Have Capacity to Make A Decision (incl. write an ACD or appoint an EG)?**

- Person is presumed to have capacity unless proven otherwise (a diagnosis of dementia does not immediately mean the person has lost capacity).
- Person must understand *the nature* and *the effect* of the decision to be made & complete and sign the document without any coercion, pressure or influence by others.
- Person must be able to communicate their decision in some way - not necessarily by speaking or writing - body language may be adequate, e.g. nodding/ shaking head .

# Incapacity is Not:

- Ignorance
- Eccentricity, cultural diversity or having different ethical views
- Communication failure
- Having a diagnosis of dementia*; depends on level
  - Mild (usually would still have capacity)
  - Moderate (may have fluctuating capacity)
  - Severe (usually would not have capacity but may still indicate when they don't want something – like a PEG tube!)
- Making what someone else thinks is a bad decision.
- Disagreeing with doctor or nurse

# Confusion About what is/is not Euthanasia

- Many problems stem from 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 – **and all are legally allowed in Australia**

# 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 studies in Qld, NSW, NT & 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

- This is often referred to as "the doctrine of double effect“ – the primary intention is to relieve pain; a secondary, unintentional effect may be the hastening of the person's death by a few hours or days.
- This is accepted by most religious and medical groups, including those who strongly oppose euthanasia.
- (Note: **not giving adequate pain relief** when it is needed may actually shorten life: the patient may suffer complications such as life-threatening cramps or severe respiratory problems if severe pain is left untreated).

# Inadequate Pain Relief:  Carers' Story

- Very frail elderly  man, fractured hip; admitted to NSW hospital; considered too frail for surgery.
  - He was clearly in agony – daughter requested pain relief /palliative care consultation; told no palliative care staff available on the weekend.
  - Nurses came to roll him – without additional pain medication; his screams drove his family from the hospital.  On the third occasion he looked at his daughter with terror in his eyes and said "Not roll. Not roll".
  - Daughter threatened the nurses with physical violence if they rolled him again – they didn't!!

# 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 (in NSW by ACD or EG).

# 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.

# "Normal" Provision of Nutrition & Hydration

- Loss of the swallowing reflex is a normal part of advanced dementia, and of the dying phase of people who do not have dementia.
- If a dying person does not want to eat or drink, this should be respected. (In Europe it is referred to as "putting down the spoon"). Even someone with advanced dementia might turn their head away or push away the food or the cup; this can be accepted as refusal.
- NOTE: EG/PR cannot refuse "normal" provision of food/fluid for a dying patient
- Families often insist on AN&H – "if we could just get him to eat something he would get his strength back" - they need information/support & counselling. (It's not OK to harm the patient in order to sooth the family).

# Artificial Nutrition & Hydration

- Finucane did a 30-year MEDLINE search of all trials of PEG feeding & found **no** evidence of positive outcomes for people with dementia re: improved survival, prevention of aspiration pneumonia, improved skin integrity, quality of life – but found strong evidence of negative outcomes, incl. site infection, aspiration pneumonia, weight gain, distress.
- Providing artificial nutrition and/or hydration to someone in the dying phase of their life can not only increase their suffering but can prevent a peaceful death.
- Research has found that AN&H interferes with the body's production of natural endorphins that ease end stage of life, and that the body produces such endorphins even in people who are unconscious or have dementia.

# Terminal Sedation

- Recent, controversial addition to the debate - terminal sedation and its relationship to euthanasia.
- Refers to use of sedative drugs to induce unconsciousness in terminally ill patients in order to relieve suffering, including anxiety, when other attempts at relief have failed. Includes withholding or withdrawing artificial nutrition/ hydration.
- Some doctors have described Terminal Sedation as "slow euthanasia" and claim that it is ethically inferior to EU because it takes patients longer to die, with the potential for further suffering.

# Some Findings from Qld & NT Studies

- Should a doctor or nurse give extra morphine if requested by terminally ill patient? More than 90% of health professionals and community members in **all studies** said that the doctor should; more than 70% that the nurse should

  (Qld) Should the law be changed to allow active voluntary euthanasia for terminally ill people who no longer wish to live? HPs/GPs – 43%/33%; Community – both 65%

- NT: To what extent do you approve of the new NT law (RoTI ACT) allowing physician-assisted suicide or euthanasia for terminally ill people?" (5-point scale, *Strongly Approve to Strongly Disapprove*)

  Medical practitioners: 35% SA/A - 48% D/SD

  Nurses : 66% SA/A – 20% D/SD

  Community members: 75% SA/A – 18% D/SD

# Qualitative Data from NT Study

- Written responses to question on approval of the RoTI 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 app*roved of the law:

  (1) "Tell the Commonwealth to keep out of our business"

  (2) "John Howard needs brain surgery".

# 4th Qld Study: (After NT study)

- Clearly defined euthanasia and asked "Do you think the law should be changed to allow **active, voluntary euthanasia** for competent, terminally ill patients who decide that they no longer wish to live?": 36% of doctors, 52% of nurses, 51% of social workers and 61% of community members said YES.
- Given qualitative comments in the NT study, we then asked respondents which of the following four statements most closely reflected their attitude:
  - I am against euthanasia (anti-euthanasia) and I don't want the law to be changed to legalise euthanasia;
  - I am not anti-euthanasia but I don't want the law to be changed to legalise euthanasia;
  - I am in favour of euthanasia and would like the law to be changed to legalise euthanasia;
  - I am neither in favour of nor against euthanasia.

# QLD STUDY 4 (Following NT Study):
# % choice for each statement

| GROUP | N | 1. Anti eu: No Change | 2. Not Anti eu: No Change | 3. Pro eu Change Law | 4. Neutral/ Not Sure |
|---|---|---|---|---|---|
| **Doctors** | **395** | 32 | **25** | 30 | 13 |
| **Nurses** | **422** | 19 | **16** | 46 | 19 |
| **S/Workers** | **306** | 18 | **20** | 44 | 18 |
| **Community** | **401** | 21 | **9** | 51 | 18 |
| **OVERALL** | **1524** | **23** | **17** | **43** | **17** |
| **P Value** | | **$\chi^2_9 = 80.33; p < 0.001$** | | | |

Depending whether I add responses 1 and 2 together, or responses 2 and 3, I can either tell you that the majority of doctors are not opposed to euthanasia, or that the majority of doctors do not want the law to be changed to allow euthanasia.

# What Really Happened in the NT

- Kevin Andrews Private Member's Euthanasia Laws Act 1997 used the Constitutional right of the Commonwealth Government to overturn RoTI 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. Churches throughout Australia asked parishioners to collect form letters from presbyteries and use as basis for submissions against euthanasia
- Kevin Andrews took a team of people around the NT, arguing against euthanasia. Evidence of misinformation and "fear-mongering".
- **12, 578** written submissions received. Commission said that **93%** were in favour of overturning the RoTI ACT (cf our population surveys).
- Analysis so far; **first 6,474** checked - detailed reading of first 500; remainder scanned for new issues & whether for or against euthanasia.
- Majority against euthanasia/in favour of overturning NT RoTI Act

# 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
- 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 am strongly opposed to the NT Act which legalises euthanasia".
- 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";
  - "I believe in the Commandment, "Thou shalt not kill"

# Qualitative Data from Individual Submissions

- Several submissions, including some on form letters, refer to "what the Nazis did". Another starts "In the 1930's & 40's Adolf Hitler practiced euthanasia …"

(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: that 60% of people in the Netherlands were euthanased (sic) without their permission. … people over 70 put off going to hospital because they fear they will not come out." (Factual, research-based evidence does not support either of these contentions).
- Some submission were both confused and 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):
  - "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.

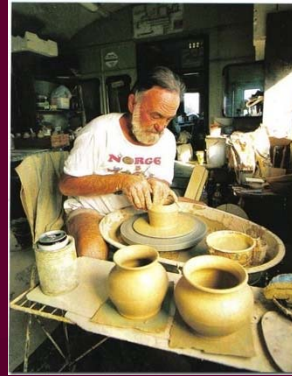
# (POSTSCRIPT)

- It had been reported to me that some Voluntary Euthanasia Societies had taken up petitions in support of the NT RoTI 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 RoTI Act, included a petition with 2,485 signatures – that was counted as 1 submission in favour of euthanasia and the RoTI 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 RoTI Act.

**(Lesson: e.g., NSW/Vic Bills - send individual letters, not petitions)**

# Thank you!

*Prof. Colleen Cartwright*



# Graeme Anderson

## Gemopal Pottery    Lightning Ridge.