



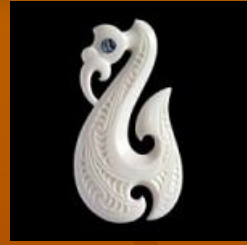
Professor Grant Gillett

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Sunday, August 14, 2016

(Plenary)

11:30 - 11:50 End-of-Life Decision-Making in NZ



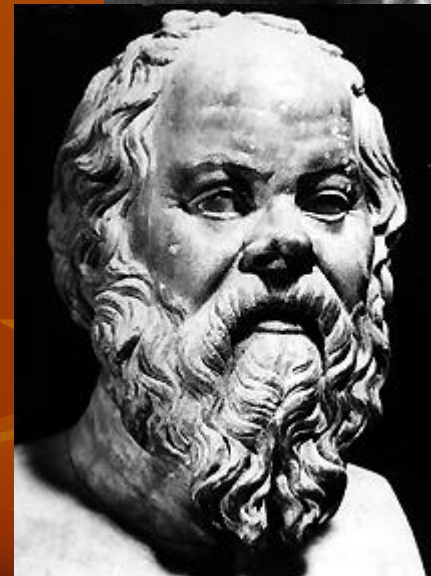
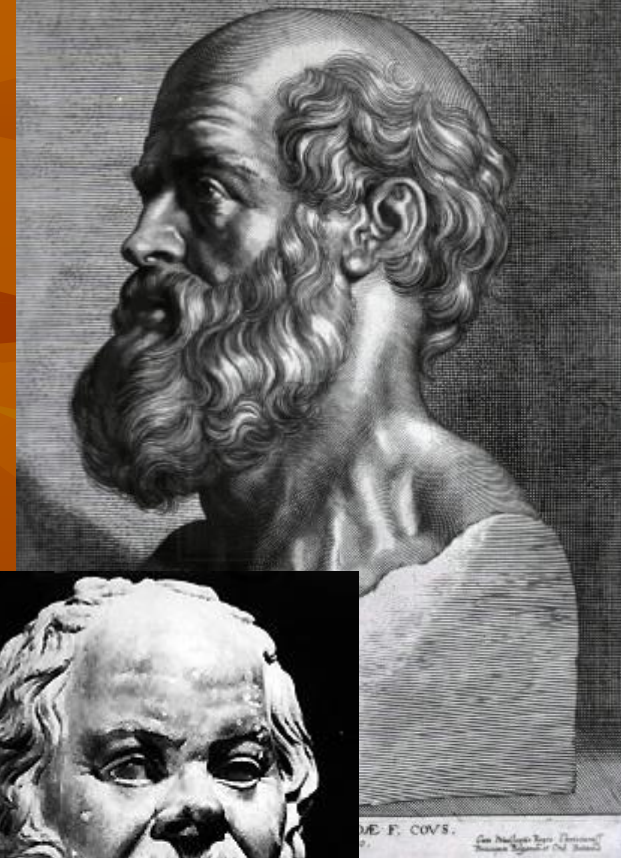
Ethics and the end of life: The current NZ situation.



Grant Gillett
University of Otago

Three principles

- Benefit or prevention of harm:
Mortality is an invariant of the human condition
- Consent or implicit consent
based on a skilled guide and companion.
- Dignity and respect
for the individual and
his or her values.



Benefit or prevention of harm

- What are the realistic prospects?
- *Substantial benefit* - an outcome which now or in the future the patient would regard as worthwhile
- The RUB – the Risk of Unacceptable Badness.

Neurotrauma and the RUB: where tragedy meets ethics and science
GillettHoneybul, Ho, and Lind *Journal of Medical Ethics* (2010 36:
727-730)

Traditional Legal perspectives

- Bland – What would the patient want?
- Mr G – What Patient would Want + subjective and objective best interests.
- Withdrawal of care & duty of care
nutrition/hydration - ?medical intervention.
- Terminal sedation
- Physician Assisted Suicide.Aid-inDying: Carter vs Canada – dignity and autonomy
 - BC decision – feeding in incompetent patient and family petition.
- ?Euthanasia and manslaughter/culpable homicide.

Lecretia Seales **FOR: I.**

- (i) Doctors are at risk from the New Zealand crimes act 1961 (#160 – murder/ manslaughter &/or 179 – aiding suicide) if they offer a patient aid in dying ;
- (ii) An absolute prohibition on aid in dying is contrary to rights 8 (not to be deprived of life) & 9 (cruel and inhuman treatment) of the New Zealand Bill of Rights Act (c.f. Carter v. Canada) .
- (iii) The protection of individual dignity is a critical value in EoL decisions.
- (iv) Existing care cannot guarantee painless dignified death.

Lecretia Seales **FOR**: II.

- (v) Patients may be moved to end their own lives earlier than would otherwise occur if their suffering seems to be worsening .
- (vi) There is no ethically relevant distinction between aid-in-dying and other EOL decisions and both are compatible with good clinical relationships .
- (vii) Aid in dying is very different from suicide because of the impulsivity, reversibility, violence and distress to others associated with the latter .
- (viii) Not all people are vulnerable and need to be protected, most are capable of exercising their own autonomy in significant health care decisions .

Lecretia Seales **Against:** I.

- (ix) The sanctity of life marks a bright line against killing human beings .
- (x) There may well be a broadening of scope beyond initial limitations if the bright line (sanctity of life) is crossed – i.e. a real slippery slope.
- (xi) Judging the worth of human lives creates a dangerous, subjective, shifting standard, sensitive to law and other social factors.

Lecretia Seales **Against:** II.

- (xii) Existential suffering and self-worth in some cultures threatens human beings and should not prompt legislative change (cf suicide rate and entrenched Maori attitudes against Aid in Dying).
- (xiii) The marginalised and disabled are already vulnerable and affected by changes in society and would be more affected by a change towards active ending of life .
- (xiv) Active assistance in dying can promote the internalisation of oppressive views of a life worth living for those who crave a sense of control.

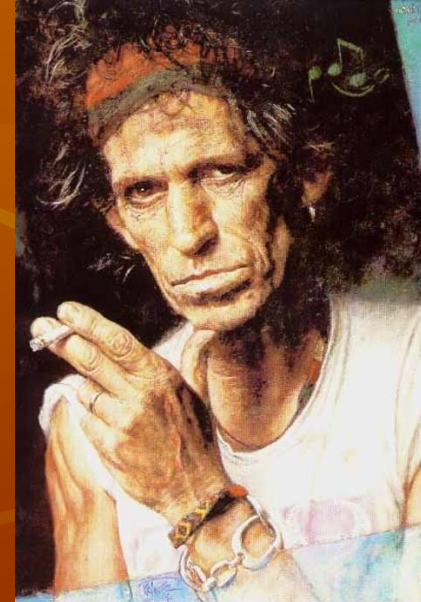
Case 1: VC

- Vanessa, 53, colon cancer, now resected and left with colostomy.
- Actually
Very socially uncomfortable
and hates mixing with other people.
- *“An horrific experience that I wouldn't wish upon my worst enemy. I no longer feel fit to be among normal people”*
- Nursing and social work assessment: coping well with ADL but keeps herself isolated ? Depressed.



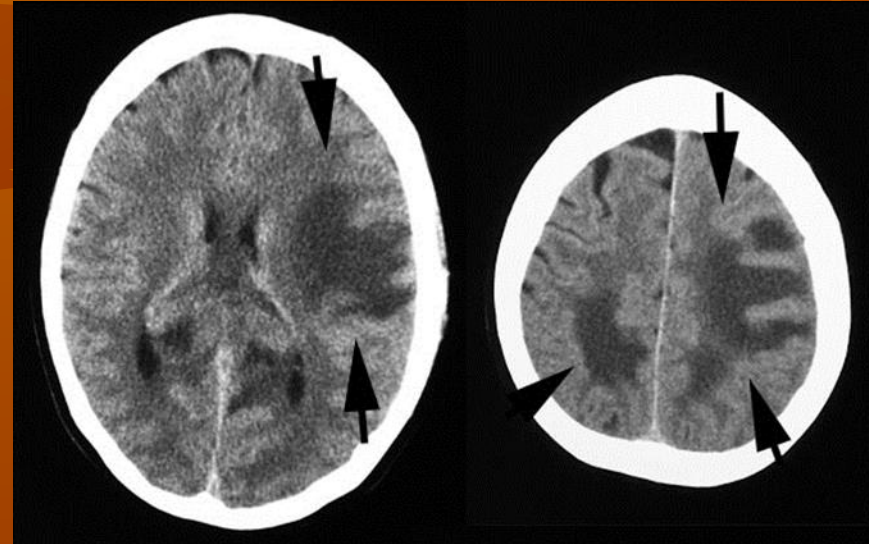
Case 2: Mr S

- Man aged 64, metastatic lung cancer, has had first seizure and MRI scan not good.
- Seizure and severely reduced conscious state
- Family argument – to survive for him would be unacceptably bad.



A human life and biological life?

- What is the human story?
 - Engaged as a being in the world =
Responds to events in the context
Complete nursing care & Artificial nutrition and hydration.
 - No significant effect from steroids.
 - ?Nobody home or ? Nobody still connected.



Locked in Syndrome

- A state in which the means of communication are lost but consciousness, thought and memory are intact.
- Results from a midbrain lesion or Guillain Barre syndrome
- The patient cannot make voluntary responses or initiate bodily actions
- Can be helped to communicate as a real person.
- **There is somebody in there!**





Lean on me!

- We all need somebody to lean on.



Recognition, Witness, holding in being.

- Being seen for who you are.
- Having your journey and its end witnessed and validated.

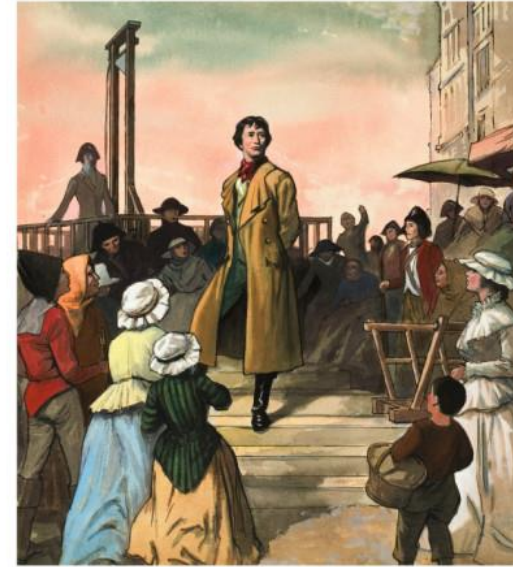


- Having someone who holds you in being.
- Consultation with relatives - Advisory not determinative.



Dignity

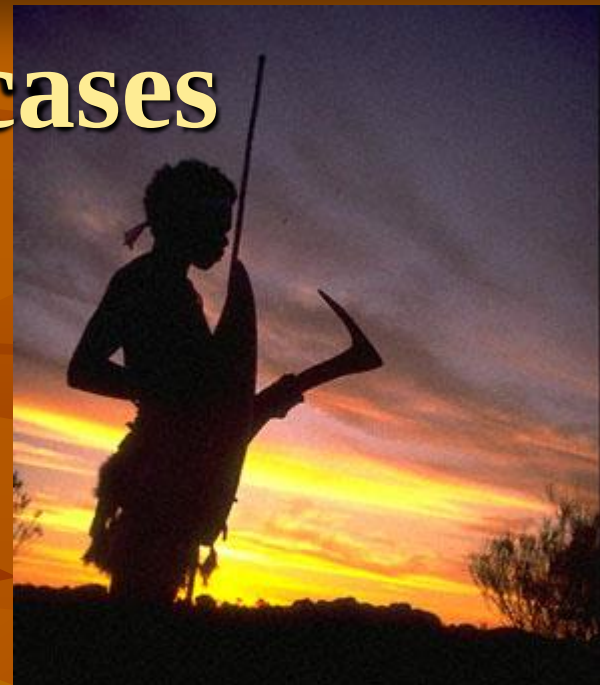
- Is this ending the right kind of ending for this patient's life?
- Would this patient want to be remembered as the kind of person whose life ended this way?
- Is what is happening consistent with the ethos of this family?



"It is a far, far better thing that I do, than I have ever done; it is a far, far better rest that I go to than I have ever known."

The contrasting cases

- We respect the person by ensuring that their life does not end in a way they would hate it to.
- The appropriate end will vary from culture to culture.
- Isolated patients (e.g. LiS) can be reconnected with the world.
- Irreversibly comatose/stuporose patients cannot reconnect to the world.
- When a person is no longer connected to this world we should not keep them here; “the spirit has a journey to go on”



At the bedside

- A duty of care properly discharged

- A being-with properly enacted

- A conversation properly had

- A life juncture properly negotiated.



Who is it who comes here?

- Finding or re-finding being-in-the-world-with-others
- Becoming somebody again
- Belonging and making something of your life-trajectory



When it is the end.

- A time to refrain from intruding.
- A time not to abandon
 - Assessment
 - Fitting response
- A time to care:
 - Relief of evident suffering
 - Indifference to risk of death



A time for the care of the living.



In sum

- The clinician cannot go far wrong who gets alongside the patient and/or those others who are closest to him or her and has a realistic and open-ended conversation about what is happening and what should be done, guided by the thought that the outcome should be one that the patient would consider worthwhile (or even, perhaps, fitting).