Ethics at the End of Life
(well philosophy more broadly really)

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What kinds of end of life issues arise in common practice?

- How would you answer that?

Overview

- Euthanasia
- Acts and Omissions, Withdrawing and Withholding
- Doctrine of Double Effect
- Futility

--- BREAK -----

- Everyday ethics in palliative care
- Death
  - What is it?
  - Does it harm us?

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Euthanasia and Physician Assisted Suicide

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Euthanasia –a good death?

- Suicide
- Assisted Suicide
- Physician Assisted Suicide
- Passive Euthanasia
- Voluntary Euthanasia
- Non voluntary Euthanasia
- Involuntary Euthanasia

Argument for all is that they are in the dying person's interests.

Voluntary, Non-voluntary, Involuntary

- Voluntary
  - performed at the express competent wish of the patient
- Non-voluntary
  - performed where the patient is unable to express a wish one way or the other
- Involuntary
  - performed against the wishes of the patient

Active vs Passive

- Active – an act is committed
- Passive – an omission to act

- This is not uncontroversial…

Passive euthanasia

In passive euthanasia death is brought about by an omission - i.e. by withdrawing or withholding treatment in order to let the person die.

http://www.bbc.co.uk/ethics/euthanasia/overview/keywords.shtml accessed 31/5/18

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Class Exercise – Healthcare Worker facilitated dying

Four arguments for

and

Four argument against

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Euthanasia – arguments for

- Suicide is allowed, and it is unfair that people who cannot kill themselves cannot choose this
- If people can refuse treatment and die slowly/painfully, should there not be a kinder option?
- People's autonomous choices should be respected, and they should be helped to die if they so wish
- Sometimes living is worse than dying, so death is preferable and should be assisted

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Euthanasia – arguments against

- Suffering can be prevented/treated without killing people
- Pressure on old, sick and disabled to die, perceived duty to die
- Slippery-slope – logical ski and empirical ski
- Medicine is about extending life and reducing suffering but not killing
- Doctors will lose their patients trust if they start killing people

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Act and Omissions: Withdrawing and Witholding

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Acts and Omissions - A Useful Distinction?

- Omission = to withhold medical intervention
- Act = to carry out a medical intervention
- If the consequences are the same is there a moral distinction?
- Is the morality in the behaviour or in the consequence?

- James Rachels – Smith and Jones

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Airdale NHS Trust v Bland [1993] AC789

- Lord Mustill:

  - ‘The English Criminal law … draws a sharp distinction between acts and omissions. If an act resulting in death is done without lawful excuse and with the intent to kill it is murder. *But an omission to act with the same result and the same intent is in general no offence at all.*’

Airdale NHS Trust v Bland
[1993] AC789

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Lord Mustill part 2

- ‘There is one important general exception at common law, namely that a person may be criminally liable for the consequences of an omission if he stands in such relation to the victim that he is under a duty to act’

- Where do healthcare workers stand in relation to their patient?

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Withdrawing and Withholding

- Both are classed as omissions to act in the eyes of the law
- Usually thought of in the context of non-capacitous patients.
- Remember an informed capacitous patients can decline any medical treatment at any time – Re: Ms B

Burke v GMC [2005]

- If a patient asks for a treatment that the doctor does not offer, and the doctor has concluded that the treatment is not clinically appropriate, then the doctor is not obliged to provide it, but should offer a second opinion.

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Ordinary and Extraordinary treatment

From Catholic Teaching

ORDINARY

- Outcome likely to be satisfactory
- Reasonable cost
- Not too painful/burdensome
- Common practice/routine
- 'nutrition, hydration, cleanliness, warmth' (includes a presumption for ANH, but not in the imminently dying)

EXTRAORDINARY

Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate

CCC 2276-2279

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GMC Guidance

- *"Not continuing or not starting a potentially life-prolonging treatment is in the best interests of a patient when it would provide no net benefit to the patient"*

Withholding and Withdrawing Life-prolonging Treatments: Good practice in Decision-making (2002) §11

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BMA

- *"Although the health care team may foresee that withholding or withdrawing life-prolonging treatment will result in the patient's death, this is fundamentally different from action taken with the purpose or objective of ending the patient's life"*

- *"...the overriding purpose or objective must be to ensure that treatment that is not in the best interests of the patient is avoided"*

Withholding and Withdrawing Life-prolonging Medical Treatment (2007)

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Futility

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Adults aged 16 years and over

DNACPRadult.1(2015)

Name

Address

Date of birth

NHS number

Date of DNACPR decision: / /

DO NOT PHOTOCOPY

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) are intended. All other appropriate treatment and care will be provided.

1 **Does the patient have capacity to make and communicate decisions about CPR?** If "YES" go to box 2 — YES / NO

If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition?" If "YES" go to box 6 — YES / NO

If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? If "YES" they must be consulted. — YES / NO

All other decisions must be made in the patient's best interests and comply with current law. Go to box 2

2 **Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:**

Futility

3 **Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:**

4 **Summary of communication with patient's relatives or friends:**

5 **Names of members of multidisciplinary team contributing to this decision:**

6 **Healthcare professional recording this DNACPR decision:**

Name _____ Position _____

Signature _____ Date _____ Time _____

7 **Review and endorsement by most senior health professional:**

Signature _____ Name _____ Date _____

Review date (if appropriate):

Signature _____ Name _____ Date _____

Signature _____ Name _____ Date _____

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Treatment Futility

- Effect (physiological) vs benefit (normative)
- Quantitative vs Qualitative

  - ‘Treatment which was either useless of ineffective
  - That which fails to offer a minimum quality of life or a modicum of medical benefit
  - Treatment that cannot possibly achieve the patient’s goals
  - Treatment which does not offer a reasonable chance of survival’

Jecker NS, Pearlman RA.1992

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Futility

- ‘A treatment which cannot provide a minimum likelihood or quality of benefit should be regarded as futile and is not owed to the patient as a matter of moral duty’?

Schneiderman LJ & Jecker NS 1993

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Doctrine of Double Effect

"Nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention. … Accordingly, the act of self-defence may have two effects: one, the saving of one's life; the other, the slaying of the aggressor."

Thomas Aquinas

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Doctrine of Double Effect

Double effect provides a framework that permits tolerance of the lesser of two evils in the following circumstances:

- The nature of the act itself is itself good, or at least morally neutral;
- The agent intends the good effect only
- The agent does not intend the bad effect either as a means to the good or as an end in itself;
- The good effect outweighs the bad effect in circumstances sufficiently grave to justify risking or causing the bad effect and the agent exercises due diligence to avoid or minimize the harm.

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Double effect

- *R v Adams[1957]* •Devlin(trial judge) Direction: "If the first purpose of medicine, the restoration of health, cannot longer be achieved there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life."

- R v Cox [1992] *"There can be no doubt that the use of drugs to reduce pain and suffering will often be fully justified notwithstanding that it will, in fact, hasten the moment of death. What can never be lawful is the use of drugs with a primary purpose of hastening the moment of death"*

DDE in Practice?

- From the Association of Palliative Medicine position statement on DDE

  - 3. There is a misconception that morphine related drugs and sedative drugs bring about death more quickly and that doctors both know this and in some way condone their use with the double effect.

  - 4. The APM refutes this claim: it knows of no credible research evidence to suggest that a patient's life is shortened either by opioids or sedatives when used in line with accepted palliative care practice

  - 5. The APM believes that DE is unnecessary to justify the use or dosing regimes necessary to manage pain or distress in all but the most exceptional circumstances.

Break

In this section

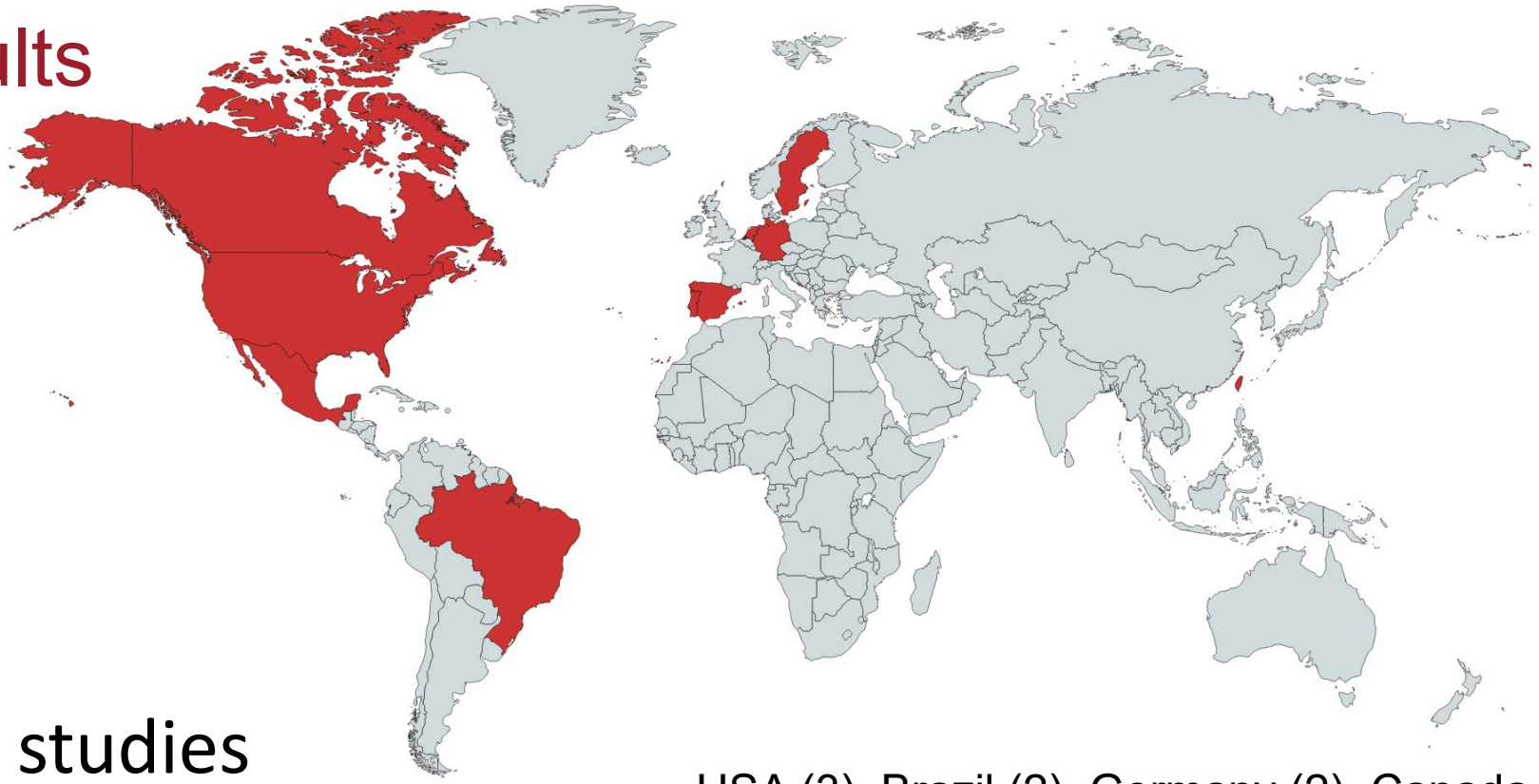
- 1. Everyday ethics towards the end of life
- 2. Definitions of death

Everyday ethics in palliative care

Background

- The topics we talked about before the break are the ‘standard’ ones - but are they the real ones?
- Ethical issues arise daily in the delivery of palliative care.
- There is a lot of literature in palliative care ethics, and an order of magnitude more in medical ethics on relevant topics eg euthanasia.
- There is a mismatch between real world dilemmas and academic literature

Results



- 13 studies
- 9 countries
- All adult palliative care

USA (3), Brazil (2), Germany (2), Canada, Mexico, Nethlerlands, Portugal, Sweden, Taiwan

Themes	Sub-themes
Application of Ethical Principles	Autonomy, Dignity, Doctrine of Double-Effect, Equity in Care, Fidelity, Truth Telling
Delivering Clinical Care	Clinical Care and Decision-Making, Communication with Patients and Families, Confidentiality, Goals of Care, Mental Capacity
Working with Families	Care and Support for the Family, Family as Decision-Makers, Genetics, Privacy
Engaging with Institutional Structures and Values	Conflict between Healthcare Professionals, Conflict with Institutional Policies, Institutional Resource Allocation
Philosophy of Palliative Care	*No subthemes*
Navigating Societal Values & Expectations	Access to Specialist Palliative Care, Assisted Dying, Conflict with Wider Societal Rules, Regulations or Laws, Cultural and Spiritual Considerations, Suicide

Clinical Care/Medical Subthemes	Description
Administration of Antibiotics	Appropriate use of antibiotics, particularly in end of life care
Advance Directives	Challenges implementing advance directives, particular when family requests may contrast with the directive
Blood Transfusions	Appropriateness of blood transfusions
Deactivation of permanent pacemakers	Appropriateness and timing of deactivation of pacemakers
Do-not-resuscitate decision making	Decision making about appropriateness of cardiopulmonary resuscitation
Electrolyte Management	Clinical decision making about management of abnormal electrolyte results
Hydration and Nutrition	A broad range of challenges related to the provision, withdrawal and withholding of both routine oral nutrition and hydration, as well as clinically assisted nutrition and hydration. Includes issues of force feeding, separately to other considerations
Investigations	What are the appropriate clinical tests to perform?
Sedation incl. palliative/terminal sedation	Ethical dilemmas concerning use of sedatives for a) symptom control, b) for continuous sedation until death.
Symptom management	Appropriate use of medication, both choice of agent and dose, balance against unwanted effects
Use of alternative therapies	Caring for patients who prefer to use alternative therapies for example traditional Chinese medicine, as opposed to prescribed medicines
Use of Opioids	Dilemmas surrounding the appropriate use of opioids, including under and over treatment, patient and clinician opiophobia.

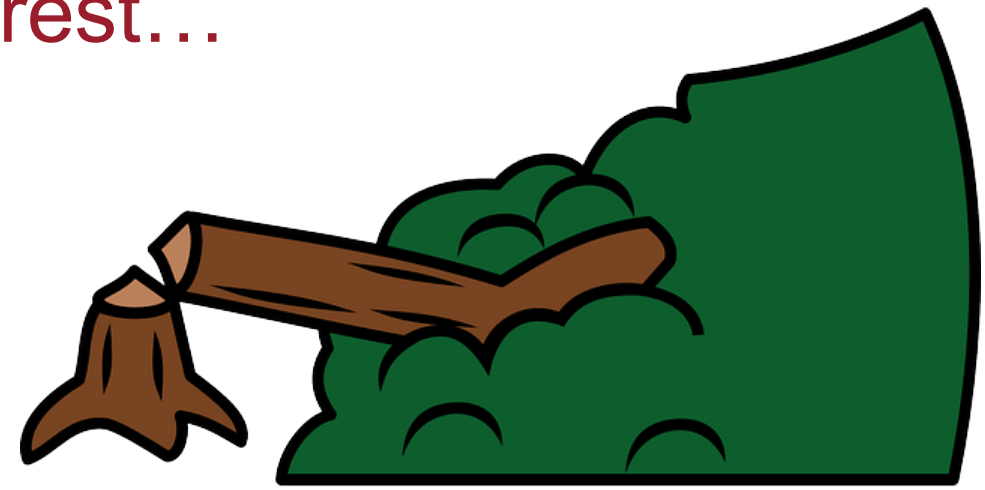
Ethics in the real world

Very broad range of issues covered

- Despite majority of world's population not being covered

- Highly context based, only 1 'theoretical theme'
  - Does this impact choices of tools or theories?
    - Deontology arguable has a harder time accounting for these details than utilitarianism
    - Feminist ethics, ethics of care better suited?

If a tree falls in the forest…



If an bioethical challenge occurs but there is no bioethicist there to hear it…did it really happen?

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Difficulties in Defining Death

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Definitions of Death

- What is death?
- When does a human being die?

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Some definitions

- Cardio-pulmonary standard
  - Prior to ventilation and defibrillators when a person's heart or lungs stopped working they suffered severe hypoxic brain damage and died or, if the initial insult was severe brain damage, particularly the brainstem, then the respiratory centres failed and they soon stopped breathing,
  - In the 1960's it became possible to replace the cardiopulmonary system with technological advances – eg cardiac bypass, artificial ventilation

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Cardiopulmonary Death

- Thus it became possible for a person with severe brain damage/brain death to have a cardiopulmonary system that could still support their organs/body

- Are they alive or dead?

- Technology created a gap between cardiopulmonary death and neurological death where previously there was none:
  - Cardiac bypass machines
  - Patients on ventricular assist devices
  - Polio sufferers with respiratory muscle involvement

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Harvard Brain Death Committee 1968

- A patient dies when they enter an 'Irreversible Coma' with no evidence of CNS activity

- This was then clarified into the Whole Brain Death standard
  - The whole of the person's brain has ceased to function permanently

- This is the neurological standard used in the majority of countries

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Problems for Whole Brain Death

- The challenge for this view is how to classify human beings that never had a brain structure in this manner, for example very early stage foetuses.

- Alternatively clinical experience has shown that whole brain dead patients can be kept ‘alive’ until their foetuses have finished gestating.

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Brain Stem Death

- Two neurosurgeons from Minnesota developed the Brain Stem definition just after the Harvard Committee published their report
- The death of the brain stem alone is enough for a person to be 'dead'

- This is the standard used in the UK

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An Artificial Brainstem

- It seems counterintuitive that the entire metaphysical nature of death should change on the invention of a machine.

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SEP: Higher Brain Death

- ‘human death is the irreversible cessation of the capacity for consciousness’

P1 For humans, the irreversible loss of the capacity for consciousness entails (is sufficient for) the loss of what is essential to their existence;

P2 For humans, loss of what is essential to their existence is (is necessary and sufficient for) death;

Therefore:

For humans, irreversible loss of the capacity for consciousness entails (is sufficient for) death.

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Higher Brain Death - Objections

- One objection to this view is in its conclusions that patients who enter a persistent vegetative state have died.

- This is counter to the very strong intuition that the warm, respiring, pulsatile bodies of these patients are alive in an important sense.

- Would society put in place all the legal safeguards post Bland if we genuinely believed these patients were dead?

- A second problem arises with anencephalic infants.

  If you never have a higher brain, can you live?

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Death is Not a Moral Concept

Singer argues that the questions have become conflated:

- 1) When does a human being die?
- 2) When is it permissible to remove organs such as the heart from a human being for the purpose of transplantation to another human being?

The definition of death is being asked to do moral work – however it is a metaphysical concept.

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Session Summary

- Case example
- Euthanasia
- Withdrawing withholding
- Acts/Omissions
- DDE – and why its not a thing
- Everyday ethics at the end of life
- Definitions of Death
- Parting thought: Does Death Harm the One Who Dies?

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Does Death Harm the one who Dies?

Should we fear death?

Epicurus thinks we shouldn't…

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Resources @ The RSM

Double effect

http://www.rsm.ac.uk/academ/downloads/double_effect_seale.pdf (Social Science)

http://www.rsm.ac.uk/academ/downloads/double_effect_levy.pdf (Neuroethics)

Webcast presentations from Dr Richard Huxtable (Law)

https://videos.rsm.ac.uk/video/killing-pain-or-killing-patients-double-effect-and-doctors-in-the-dock

and Dr Nigel Sykes (Palliative medicine) on the RSM video channel

https://videos.rsm.ac.uk/video/is-the-principle-of-double-effect-still-relevant-in-end-of-life-care

The Assisted Suicide Debate Videos

https://videos.rsm.ac.uk/video/debate-for

https://videos.rsm.ac.uk/video/debate-against-this-house-believes-that-assisted-suicide-should-be-legal-in-the-uk

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Should we fear our Own Death?

1. The Harm Thesis

2. Epicurus
   - Letter to Menoeceus
   - Challenges locating the harm

3. The nature of harms
   - Deprivation as a harm?

4. Comparativism

5. The Timing Problem

6. The Cambridge Change

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The Harm Thesis

- This is the claim that death can harm the individual who dies

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Epicurus (341–270 BCE)

- Epicurus was an ancient Greek philosopher as well as the founder of the school of philosophy called Epicureanism.
- For Epicurus, the purpose of philosophy was to attain the happy, tranquil life, characterized by ataraxia—peace and freedom from fear—and aponia—the absence of pain—and by living a self-sufficient life surrounded by friends.
- He was a positive hedonist and taught that experienced pleasure and pain are the only measures of what is good and evil;

Epicurus

- ‘Death, therefore, the most awful of evils, is nothing to us, seeing that, when we are, death is not come, and, when death is come, we are not. It is nothing, then, either to the living or to the dead, for with the living it is not and the dead exist no longer.’

- Epicurus in a letter to Menoeceus

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The problem of the timing of the harm

- Epicurus - base of his argument:

- The classic view of a harm is that it must be experienced to be harmful and thus has:
  - A subject
  - A time that it occurred

- Eg stubbing one's toe

- The subject is clear when one is alive, but more difficult if one accepts the premise assumption that there is nothing after death

- The timing is also difficult. Either death harms us whilst we are alive, or harms us in some way after we die

Ongoing Timing Trouble

- Further premises:
  - A person cannot be causally affected by a future event
  - What occurs before I exist might well affect me but only whilst I exist
  - Events can only effect someone by having a causal impact on them
- Philosophers rarely agree on anything but this is something most are very keen to defend!

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Nagel on Death and the nature of its harms

- Nagel points out that clearly if it is to harm us it is through those things that it deprives us of.

  - He expands this to say that simple organic survival does not form part of this – arguing that all other things being equal there is little to choose between instant death and a coma for 20 years and then death

Thomas Nagel. Mortal Questions, 1979

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Deprivation as a Harm (1)

- Imagine the following scenario:
- Your friend is given her ticket and your ticket for the party of a lifetime.
- She then decides not to invite you, even though you would have very much enjoyed that party. You are never aware that there was an invite for you too.
- It seems intuitive to say that you are worse off because you were not able to go to the party and your so-called friend caused this harm through a deprivation

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Deprivation as a Harm (2)

- Nagel describes this as the ‘what you don’t know can’t hurt you’ argument

- He argues that if this holds then the follow is true:

Imagine a man who is betrayed by his friends, ridiculed behind his back, and despised by people who treat him politely to his face

- can be said to be a misfortune so long as he remains unaware and does not directly suffer as a result?

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Comparativism

- Imagine two worlds:
  - a) Where S dies at time T
  - b) Where S survives

- Compare the total amount of welfare for S across the two worlds, and the better world is the one with more

- This will usually be B, hence S' death harms S

- The deprivation of the goods S would have experienced is the harm visited on S when she dies in world A

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Comparativism vs Epicurus

- A key feature of the comparativist approach is the idea of a deprivation as a special kind of harm that is both implicit in a very wide range of ordinary, confident evaluative judgments.

- This is not easily reconcilable to the ‘Epicurean’ perspective on which only bad experiences can be thought of as harms.

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A quick note on what is welfare? – Three major definitions

- **Positive Hedonism** – S's experience of pleasure at time T is the only thing that is intrinsically good for S at time T. Pain is the only intrinsically bad event. The more pleasure at time T, the better the event. (Mental Statism)

- **Preferentiallism** – Welfare is improved when desires are fulfilled. S's welfare increases at T if at T, S desires P and P holds. For example, wanting to be a well thought of writer

- **Objective List Accounts** – A person's ultimate goods and bads are related to an objective list based outside the person. What these might be is up for debate…

- Comparativism works for all three, even if each of the three has its own problems.

The Timing Problem

- Possible solutions to the timing issue:
  - **Subsequentialism**
  - **Indefinitism**
  - **Concurrentism**
  - **Eternalism**
  - **Priorism**

- One argument in support of the comparativist here is that the timing problem is implicit in the general idea of a deprivation harm…

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The Cambridge Change

- Geoffrey Scarre takes the argument another way…
- He argues that people cannot undergo intrinsic changes in welfare after their deaths but can undergo relational changes (Cambridge changes).
  - Eg. Non-brother to brother
- These changes can be undergone even after death e.g. tallest person in history

  - if this was the person's life ambition to be remembered as this and then someone taller was born this could be argued to be a harm to them (preference satisfaction welfare)
- No subject needed as no intrinsic properties changed and time point is easily identifiable.

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Summary

- In summary:
- Epicurus argues that death is not to be feared as although dying might be (briefly) unpleasant you don't exist at the time you are dead and so nothing can harm you
- He poses that challenges of:
  - Lack of subject
  - Lack of time
- Many different philosophers have tried to argue against this – but all appeal to more removed intuitions
- Should you fear your own death? (As opposed to the dying process)