Ethical Issues in EOLC

including withdrawing/withholding artificial hydration/nutrition

As part of the Principles and Practices of EoLC

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Structure of The Session

- Overview of Ethical Theory
- Practical Ethics
- What is ‘Dead’?
- Law Around the End of Life
- **Comfort break!**
- Withdrawing Treatment (including artificial feeding and hydration)
- Doctrine of Double Effect, Sedation in EoL; *not covered due to time constraints*

What is Ethics?

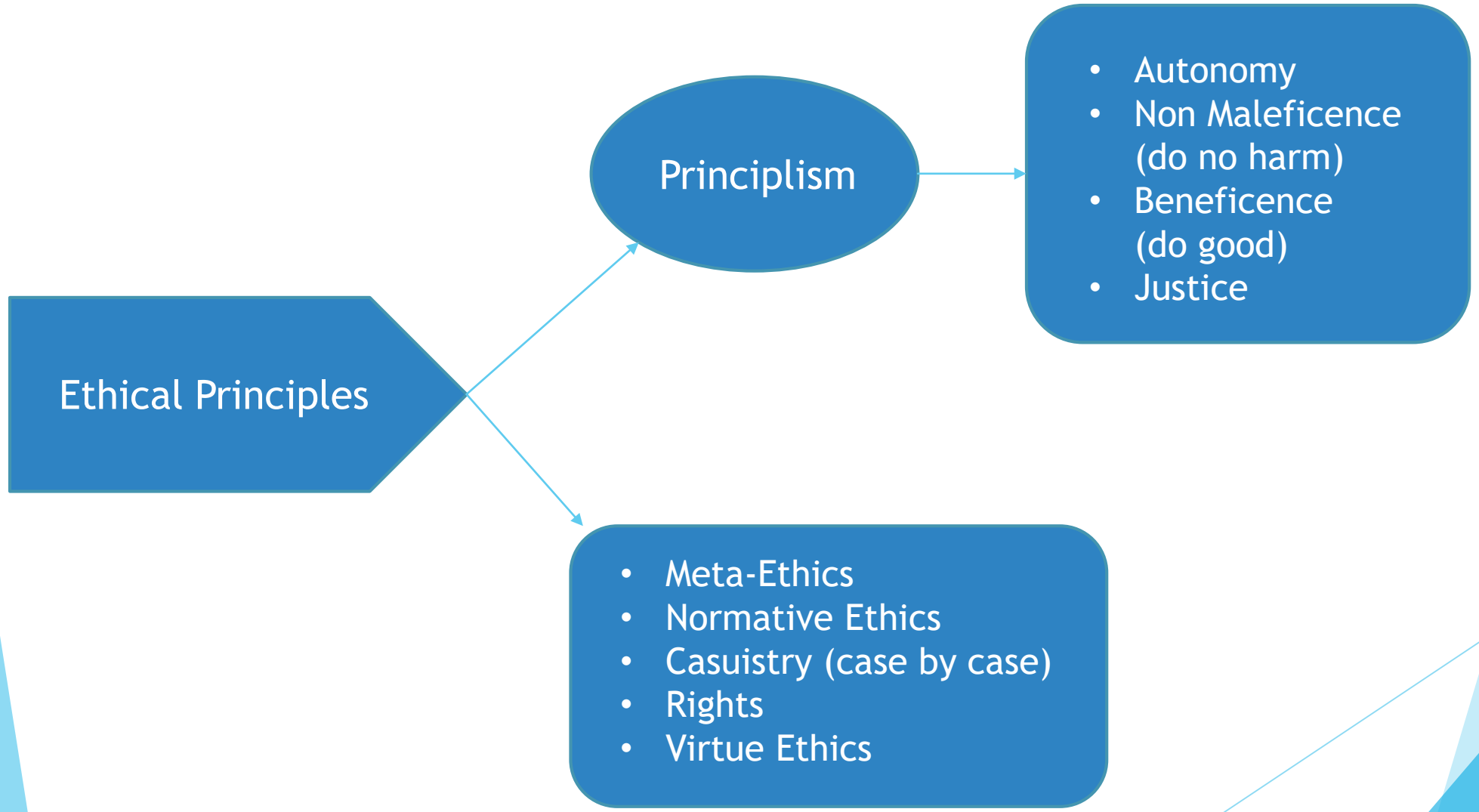
- Ethics is the *pursuit of the right or the good*.
- Ethics make up the fibre of our lives as human beings. We are moral animals with free will, moral responses, duties, judgements and a deep concern that what we and others do is *right*

Does the ‘doctor know best’?!

What should we consider to make good decisions?

- Patient rights (including Human Rights)
- Practitioner responsibilities (GMC, NMC etc)
- List of principles of difficult cases?
- Law? Is what is legal always ethical?

An Overview of Ethical Theory



Meta-Ethics

- Theories **about** ethics rather than theories **of** ethics
- Not intended to guide conduct but to consider exactly what ethics is
- In what way is it possible for ethical judgements to be true or false

- E.g Is morality relative?
- **Relativism**: Theory that moral truths are relative to culture & society

Appealing as apparently liberal and tolerant of other cultures

Central idea is that what is right for one culture may simultaneously be wrong for another

- **What do you think?**

Greeks and Callations

- The Greeks believed it was wrong to eat the dead, whereas the Callations believed it was right eat the dead
- Relativism would say eating the dead is neither objectively right or objectively wrong. It is merely a matter of opinion which varies from culture to culture
- How does this fit with cultural/religious beliefs seen in our practice? E.g. Family wishes to ‘preserve life at all costs?’

Objectivism

- Opposite to relativism
- Objectivists hold that there is a single moral fact about whether it is morally permissible to eat the dead.
- The objectivist recognises that there is variation in what people of different cultures believe is right and wrong but hold that this variation does not represent a variation in the truth

Normative Ethics – relating to an ideal standard or model, ‘how ought I to live?’

Consequentialism

- Is an act right or wrong? That all depends on the consequence.
- The right action is the one that produces the best overall consequences.
- Any action can be justified provided the benefits outweigh the harms
- **E.g Jim and the Indians**

Problems

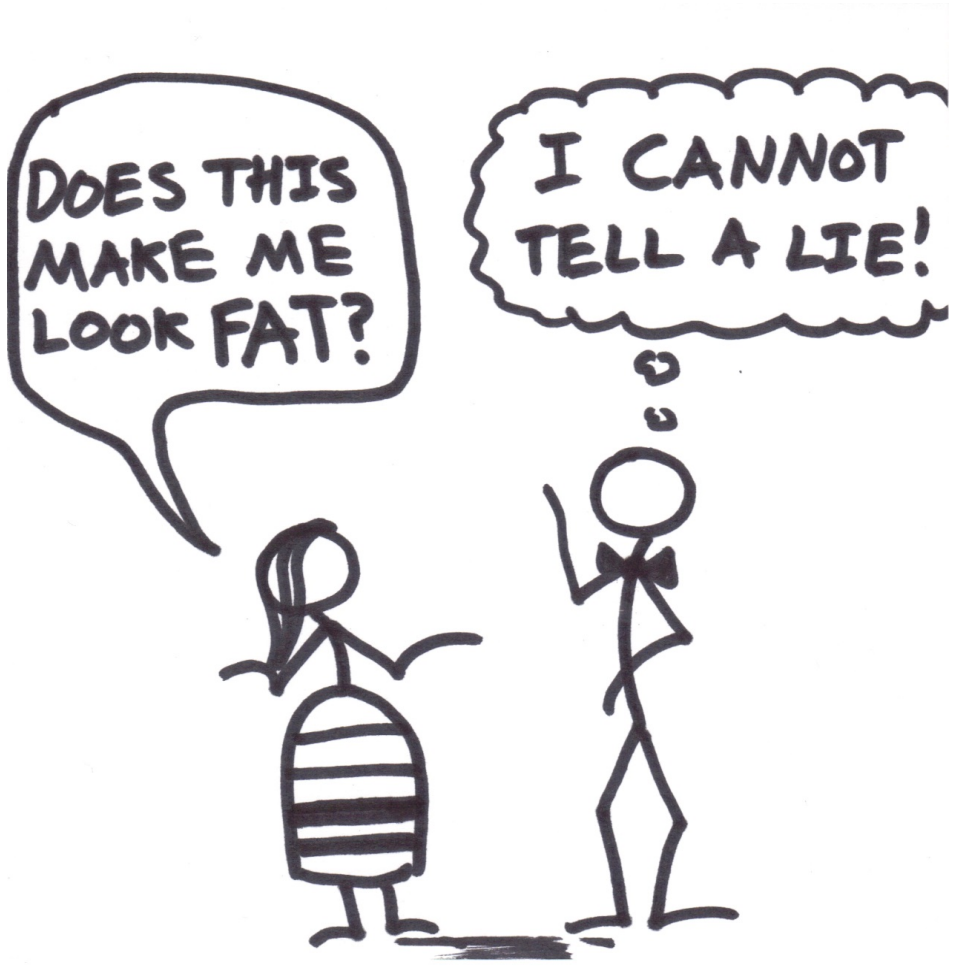
- Forbids nothing absolutely as long as it promised the best consequences (torture, murder etc)
- Difficult to live by: have to calculate the consequence of every outcome, ‘moralistic computers’

Deontology

- The view that some kinds of action (e.g. killing, deceiving) are wrong **even if the benefits they produce exceed the harms**
- What is right is not to be defined in terms of what is good

e.g. Lying- it is not the badness of the consequence of a particular lie, lies are wrong because of what they are

e.g. It may never be right to intentionally kill someone regardless of how much good may be produced.


DOES THIS MAKE ME LOOK FAT?
I CANNOT TELL A LIE!

Problems with Deontology

- What makes something wrong and why is it wrong?
- Constraints need to be narrowly framed (is withholding the truth a lie?)

An HIV positive patient refuses to tell his wife and continues to have sex with her. Should you tell his wife?

- **Consequentialist**? Yes, husband may be distressed but the greater good is infection prevention
- **Deontologist**? No, absolute duty to respect confidentiality regardless of consequences

Utalitarianism

- Equates utility with usefulness in promoting pleasure / avoiding pain
- Classically is hedonistic
- Originally proposed as a guide for public policymakers

Virtue Ethics

- Morality centres around the moral agent not the action or the consequence ‘Doing the right thing for the right reasons’
- The ultimate aim is to live a good life, including living a moral life by making rational decisions habitually by means of a good character
- It asks ‘What kind of person should I be’ rather than ‘What ought I to do?’ or ‘What is good?’
- E.g. DNAR form

Principlism

- System of ethics based on the four principles of:
- Autonomy
- Beneficence (Do Good)
- Nonmaleficence (Do no Harm)
- Justice

- Compatible with most intellectual, religious & cultural beliefs
- First formalised in the Belmont Report in 1979, prompted by criminal proceedings of war crimes against humanity by German Physicians during WWII.

1. Autonomy

- Most important principle?
- Patients have the right to make decisions over the treatments they receive
- No one can give a treatment without a patient's consent if patient is competent
- The decision can be foolish or perverse but still stands.
- Can a patient demand a treatment?

- St George's Healthcare NHS Trust v S [1998]
- S was 35 weeks pregnant and needed a caesarian section but refused knowing that the child might die. S had capacity. Hospital sought legal decision, given go ahead by High Court judge. Baby born and all well. Mother then sued.

2. Non-Maleficence (do not harm)

- Healthcare workers must not harm their patients. So obvious it hardly needs stating?
- Physical harm
- Psychological harm

3. Beneficence (Do Good)

- Tricky area, what if doing the best is very expensive?
- Normally interpreted as health care professionals doing the very best given the resources available.
- Cannot force the best treatment on a patient if they do not want it.
- What if a patient objects to a proposed treatment and wants one that is less effective?

4. Justice

- Most people agree that people should be treated justly, but what does this mean?
- In theory, one patient should not be given preferential treatment over another. In practice, can this always work?
- Issue of expensive treatments

e.g. NICE decisions on recommending advanced oncological treatments

e.g. What if elderly get very expensive treatments for glaucoma yet child health clinics are closing?

- How does Justice work with Autonomy?

A few more approaches

- **Rights**

The notion of rights in medical ethics is partly due to the Human Rights Act 1998

Very difficult to define

If you have a right to vote for example, other people are bound by a duty to protect or promote the interests of the person who can vote. There must be good reason why that person should be prevented from voting.

The European Convention on Human Rights; impacts on medical law include:

Article 2: Right to Life

You must not intentionally kill a patient

Article 3: Right to protection from torture, inhumane or degrading treatment

You must not where possible leave a patient in a degrading state

Article 5: Right to Liberty (? discharge planning)

Article 8: Right to respect for family life

e.g Involve parents when treating children. Promote patients' wishes to be with family on discharge planning

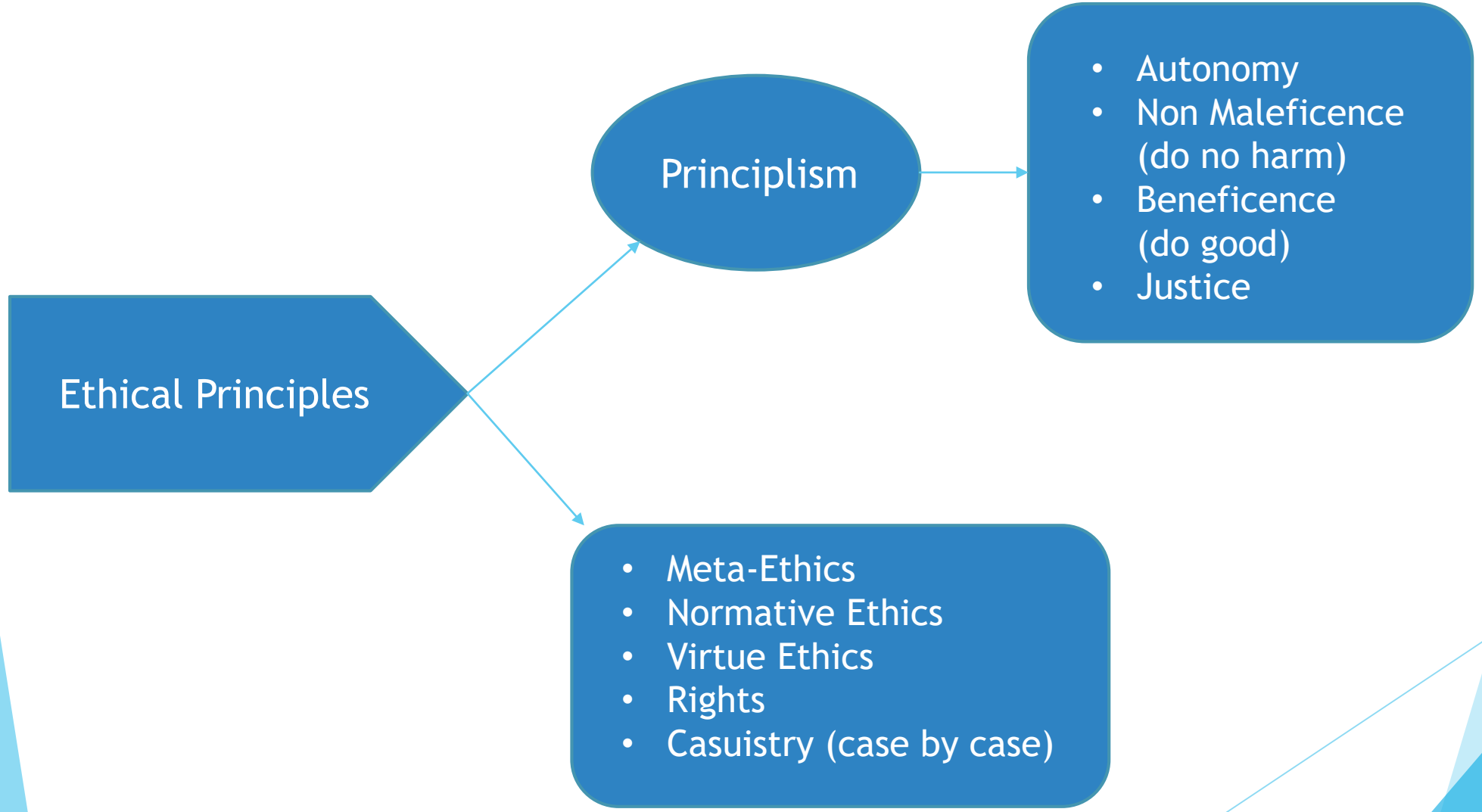
Article 14: Right to not be discriminated against

Healthcare resources may not be allocated based on age/gender/sexual orientation/race/other protected characteristics

Casuistry (Case by Case)

- Case based reasoning. Each case is different
- Often used in law
- For a casuist **the circumstances of a case are essential for evaluating the proper response**
- Usually begins with a clear cut case (paradigmatic case) e.g. Premeditated murder in a legal case. Then treat future cases depending on how closely they resemble the paradigmatic case
- **Theory modest:** Practitioners agree certain paradigms are treated in certain ways then work from there

An Overview of Ethical Theory



Applied Ethics

- Systematic approach to practical moral problems
- **The interface between practice and theory**
- Often concerns controversial matters or policy implications

e.g Euthanasia

- It matters that the right thing is done but it is not obvious what that is
- Addresses what our moral aims should be, what the value of life is, who has moral responsibility and the definition of death

e.g. Dignity

- Central to many ethicists' views
- Vague term: what is it about us that makes us human and requires us to respect each person's unique status.
- Is it dignified to leave someone unwashed even if they are happy in that state?

Ethics on a Daily Basis

- Accessing senior advice appropriately
- Responding to competing demands on time
- Talking to families who are frightened or angry
- Dealing with frustrating, unlikeable or ungrateful patients
- Considering how to react when colleagues are unprofessional or inappropriate in their own behaviour or towards patients
- Other examples?
- **May not relate to ‘dilemmas’ or momentous decisions, more often it is a series of small everyday choices and incremental decisions that may not even be conscious.**

The definition of death

- How is death defined in law?
- Until recently death was uncontested, why has this changed?
- Technology: Ventilation, transplantation, resuscitation
- The definition of death is also important in relation to transplantation, murder and burial


What is death?
Process
Loss of interaction
Desoulment
Total cell death
Death of organs
No breathing
Death of brain stem

What is dead?

- Cessation of breathing? What are the problems with this definition?
- Once every cell stops working?
- Social death? Loss of consciousness and social interaction? What about disorders of consciousness / dementias / ventilated patients?
- Desoulment? What does it mean? How is it defined? When does it occur?
- Death as a process?

Academy of Medical Royal Colleges 2010

- **5 MINUTES**: Absence of central pulse on palpation / heart sounds on auscultation
- "Continued Cardiorespiratory Arrest" → absence of pupillary responses to light; corneal reflexes; motor response to supraorbital pressure should be confirmed

- **Brain Stem Death** (Coma)
- Irreversible loss of the **capacity for consciousness (wakeful but not aware)** + **capacity to breathe** (req ventilation)

Criminal Law and Ending of Life

- A nurse or doctor is guilty of murder if….
  - You cause the death of the victim AND
  - You intend to cause the death AND
  - You cannot raise a successful defence

- In medicine it can be difficult to know if drugs have caused a death
- Hastening a death by a few hours is still murder
- **Death by Omission**: Ending Life by **not** doing something


HEAT

Hillsborough Disaster

- On the 15th of April 1989 Liverpool was playing Nottingham Forest for an FA Cup semi-final at Sheffield Wednesday's Hillsborough football ground. Traffic delays had led to many Liverpool fans arriving late and in the moments prior to kick off there were several thousand fans outside the turnstiles. As a bottleneck developed outside the ground, police, fearing a crush, opened a set of gates leading in to a narrow tunnel at the rear of the terrace. Fans streamed down the tunnel into the already crowded central section of the terrace. At the front of the terrace fans were pushed and crushed against steel fencing installed to prevent hooliganism.
- 96 people died as a result of the crush at Hillsborough with 766 injured.


THE Sun
THE TRUTH
Tycoon Adnan thrown in jail
GATES OF HELL
•Some fans picked pockets of victims
•Some fans urinated on the brave cops
•Some fans beat up PC giving kiss of life
DI GRIEVES FOR LEE, AGED 14: Pages 2 and 3


THE Sun
BRITAIN'S MOST POPULAR PAPER
WILLS: Two kids with Kate would be great
23 YEARS AFTER HILLSBOROUGH..
THE REAL TRUTH
● Cops smeared Liverpool fans to deflect blame
● 41 lives could have been saved, says new probe
● Sun: We are profoundly sorry for false reports
● Families of 96 victims call for prosecutions

Omission Causing Death: Withdrawing Treatments

- Hillsborough Disaster **led to a critical change in medical law**
- Airedale NHS Trust vs Bland [1993]

Tony Bland had been in a coma for 3 years since he was crushed at Hillsborough. He was in a persistent vegetative state. Family and medical team asked for permission to switch off life support and withdraw feeding and fluid.

- Was he still alive?
- Was withdrawing food and fluid an ACT or an OMISSION?
- Was hydration in his best interests?
- Do patients in PVS have best interests?

- Judges agreed that “it is perfectly reasonable for the responsible doctors to conclude that there is no affirmative benefit to Anthony Bland in continuing the **invasive medical procedures** necessary to sustain his life. Having so concluded, they are neither entitled nor under a duty to continue such medical care. Therefore **they will not be guilty of murder if they discontinue such care**.” Treatment was stopped and Tony Bland died on March 3rd 1993.

Patients Refusing Treatments

- Refusal of Medical Treatment [2002]: Mrs B, 41, paralysed from neck down and ventilator dependent. She asked for it to be switched off.
- Does she have this right? What should the medical team do?
- Absolute right to refuse treatment even if it is not perceived to be in her best interests **as long as she is competent.**
- Appointed Lasting Power of Attorney for Health and Welfare in valid and applicable circumstances, also has this right on behalf of the patient if they no longer have capacity.

Suicide and Assisted Dying

- It is not an offence to commit suicide.
- It is an offence to help someone commit suicide.
- Do we have the right to be killed or helped to commit suicide?
- Pretty v Director of Public Prosecutors [2002]: Diane Pretty had motor neurone disease. Wanted DPP to declare that if her husband helped her commit suicide he would not be prosecuted. DPP refused. Then went to the House of Lords then European Court.
- Outcome: Had a right to life but not a right to be killed.

- Later case Purdy vs DPP [2009]: prompted clearer guidance on whether carers would be prosecuted (now includes evidential and public interest stages)

- Assisted dying remains illegal in the UK as does aiding a suicide.

Mr L and his morphine

- Mr L has end stage heart failure
- You don’t expect an improvement in his condition
- He is breathless from his pulmonary oedema
- He is struggling to take oral medications
- He says to you: ”you wouldn’t treat a dog like this – can’t you just give me an injection to end it all?”
- How do you respond?

On the other hand, can you obtain an order to stop withdrawal of treatment?

- Burke vs GMC [2005]
- Mr Burke had cerebellar ataxia. It was predicted that at some point he would need artificial hydration and feeding. He was concerned that if he lost capacity, this would be withdrawn and he would die. He requested an order to ensure this did not happen.
- Outcome? If capacity is lost, then best interests becomes a deciding factor.
- You cannot insist on treatment **whether you do or do not** have capacity.

Comfort Break!

Clinically Assisted Nutrition and Hydration (CANH) vs Basic care

- Mental Capacity Act distinguishes between basic care (oral intake including sips of fluid, washing, warmth) and treatment.
- Basic Care cannot be refused in advance.
- CANH is a treatment.

Clinically Assisted Nutrition and Hydration (CANH) – A Very Brief Overview

- First thoughts in EoL setting?
- Those in favour?
- Those against?
- Why?
- What helps us decide? Evidence and Guidance?

Challenges

- Guidance can be unclear with internal conflict: ‘Best Interest’ medical decision v family
- GNC: No guidance produced, not seen as a nursing issue
- Previous guidance in Liverpool Care Pathway (LCP) abolished in 2013, driven by appalling findings at Stafford → Francis Report (Baroness Neuberger) 2013
- Marked lack of evidence base (reiterated by 2 Cochrane Reviews 2008; 2013); authors from narrow interest base
- Influence of populist press


Systematic Reviews
Randomized Controlled Trials
Cohort Studies
Case-Control Studies
Case Series, Case Reports
Editorials, Expert Opinion

Summary of the Evidence

- 40 papers to consider (2 good, 11 bad, 27 ugly)!!
- Large accumulation of poor to very poor evidence that CAH benefits some, harms a few, has no effect on most.
- Moderate evidence from 1 study: No evidence of impact on symptoms, quality of life or mean survival if CAH used in last days of life. BUT small study, struggled to recruit and statistical power is weak.
- 2 Important Studies:
  - Rio 2012, Cohen 2013
  - Emotional Impact of reduced oral intake on relatives and healthcare staff
  - Families perceptions of the benefits of CAH

Findings

- Vast majority see CAH important in slowing dying process
- Cultural differences are strong
- Families who forced patients to eat and drink were less accepting of impending death
- Families relaxed about CAH spent far more time in caring and nurturing roles
- Families perceived not giving CAH as medical negligence
- Hospice staff viewed CAH less favorably than hospital staff
- Cohen found overwhelming majority of families seeing CAH as beneficial

NICE EoLC for Adults, updated 2017

- Concludes that evidence is lacking for CANH
- Recommends discussing risks and benefits of hydration with patient & family
- Advise patient and family that CAH may relieve the distress of dehydration but unlikely to prolong life or the dying process
- **Death unlikely to be hastened by not having hydration**

Treatment and care towards the end of life: good practice in decision making GMC 2010

- “If a patient is in the end stage of a disease or condition, but you judge that their death is not expected within hours or days, you must provide CANH if it would be of overall benefit to them”…
- …”taking into account the patient’s beliefs and values, any previous request for nutrition and hydration by tube or drip and any other views they previously expressed about their care.”
- “The patient’s request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.”

Withholding hydration and nutrition GMC 2010

- Consultant in Charge is decision maker taking into account:
  - Not just clinical considerations
  - Those close to patient help inform what the patient would have wanted
- “The benefits of a treatment that may prolong life, improve patient’s condition or manage their symptoms must be weighed against the burdens and risks for that patient, before you can reach a view about its overall benefit.”

An Important Distinction

- “The ethical situation is not that the patient is failing to drink and will therefore die but that the patient is dying and therefore does not wish to drink”

Lennard-Jones JE. Giving or withholding fluid and nutrients: ethical and legal aspects. JR Coll Physicians Lon 1999;33:39-45.

- Just because you can does not mean that you should

Mr R: Withholding assisted nutrition when lacking capacity

- Mr R is a 75 year old man and has had dementia for some years
- He is now immobile and unable to swallow
- A decision needs to be made about whether to feed him by clinically assisted means
- He is assessed to lack capacity for this decision
- What factors need to be taken into account?
- What is the evidence for CAHN in this setting?
- What do you think is the right thing to do?

CANH in those without capacity BMA/RCP Guidelines Dec 2018

- Covers (re)starting, continuing, stopping CANH
- **No legal difference between stopping feeding/not starting feeding (need 2nd opinion in both)**
- ENGLAND & WALES
- **Not relevant if days/hours prognosis** / CANH not clinically indicated / Does not cover oral feeding
- CANH is part of broader decision about life-sustaining treatment
- Only to provide when in patient's Best Interest: *Clinical* and *Personal* info required consulting 'Anyone interested in welfare': family, friends, HCPs, carers, neighbours, Court Deputies, IMCAs. Check ADRT/PoA for guidance.
- Otherwise, clinician led BI decision-making process +- independent 2nd opinion.
- **Court of Protection NO LONGER required if there is agreement of all parties**

Questions?

Thank you!

Doctrine of double effect

- DDE appeals to a distinction between effects of an action that are intended, either as an end in themselves or as a means of achieving some end, and **bad effects that are merely foreseen**
- Has its origin in Roman Catholic moral theology to reconcile killing in self defence or a just war with the belief that killing the innocent is always wrong- it is sometimes permissible to act in a way which forseeably causes the death of an innocent person although it is never permissible to intend such an outcome

Doctrine of Double Effect

- Most accounts include four conditions and **all four conditions must be met** in order to render permissible an action which produces a bad effect that it would be impermissible to bring about intentionally

1. The act must be good, or at least morally neutral (independent of its consequences)
2. The agent intends only the good effect. The bad effect may be foreseen, tolerated and permitted, but it must not be intended
3. The bad effect must not be the means to the good effect
4. The good effect must outweigh the bad effect (proportionality clause)

Beauchamp and Childress 1994, p207

Ethical problems with the DDE

- Moral significance of the intention/foresight distinction- are we responsible for all the foreseen consequences of our actions, whether or not they form part of our plan?
- Problem of redescription
- Problem of application- how do we know what intentions are?