

# Legal Issues in Paediatric Palliative Care

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# Learning objectives

- Describe the concepts of life and death and the law
- Identify the essence from legal perspective related to paediatric palliative / end of life care
- Raise the awareness and recognize the obligation in the care delivery process

# Fundamental principles

- **Preservation of life**

≠ offer all available means

≠ mere suspension the act of dying

- **Best interest for the patient**

# Background

Legal and ethical issues that pertain to death, dying and end of life decision making are increasing complex today because of :

- **Technological advancement**
- **Human rights**
- **Social development**

- The recognition of **a right to life** and **protection from harm** is one of the main ideals in a civilized society and thus it has the **protection of law**
- **Individual autonomy** often regarded utmost importance and **surpasses** the competing cardinal virtues, including sanctity of life or medical best advice
- Patient autonomy is an important and empowering principle for **competent individuals**

What rights a  
competent person  
possesses ?

# Hong Kong Basic Law

## Article 4

- The Hong Kong Special Administrative Region shall **safeguard the rights** and freedoms of the residents of the Hong Kong Special Administrative Region and of other persons in the Region **in accordance with law**.

## Article 39

- The provisions of **the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights**, and international labour conventions as applied to Hong Kong shall remain in force and shall be implemented through the laws of the Hong Kong Special Administrative Region.

# Hong Kong Legislations

## **Cap 383 Bills of Right Ordinance**

- **S 8 Hong Kong Bills of Rights**
- Article 2 : Right to life
- (1)Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life.



# Hong Kong Legislations

## Cap 212 Offences Against the Person Ordinance

- s33A Suicide to cease to be a crime
- The rule of law whereby it is a crime for a person to commit suicide is hereby abrogated

(added 71 of 1967 s2)

# How about infants and children ?

- Infants and children cannot express their rights, values and choices



**Decision making for this group is one of the most profound ethical, legal and medical minefields of our time**

- Unlike competent patients, infants cannot express their wishes or choices in relation to medical treatment, articulate their individual autonomy or consent or refuse treatment
- All decisions for **this vulnerable group** would be made by **their parents/ guardians**

- The **parents** of a baby or young child are **legally entitled** to decide what the medical treatment their child will- or will not- have, provided that they act in the **child's best interests**

(Skene, 2008)

- Where parents disagree with either the discontinuation or continuation of medical treatment recommended by the medical practitioners, **the court has the inherent power to make orders and determinations with the child's welfare as its paramount considerations**

# Best interest

- Lack of any normative basis on which the best interests principle can be established
- **But “Best Interest” remains the benchmark for deciding life and death decision for patient**
- While determining whether the continuation of life sustaining treatment is in the best interests of a patient, medical practitioners and the court also consider **the concept of futility**

# Futility

- The concept of futility is an inexplicit and ambiguous as the best interest principle
- Both concepts are overwhelmingly **co-dependent** and the application of the terms remain a central issue in end of life decision making today

# Futility

- Futility conveys a judgment about the **worthwhileness of providing or continuing treatment**
- It is ethical controversial because what is worthwhile can only be assessed relative to its goal
- Futility implies a quality of life judgment, a judgment about whether it is worthwhile to keep the patient alive



# Early Case Law from UK

- R v Arthur (1981) 12 BMLR 1, concerned a reported criminal prosecution in relation to a doctor withholding care from an infant born with Down syndrome
- Dr Arthur had provided nursing care only but with a strong painkiller DF118 and letting nature takes its course
- Dr Arthur claimed **his main intention of prescribing DF118 was to alleviate any suffering the infant may have endured**
- He was charged of murder and the reduced to attempted murder

# R v Arthur (1981) 12 BMLR 1

- Justice Farquharson's reasoning by establishing a criterion justifying ending the life of an infant in the instance 'where the child is irreversibly disabled and .... rejected by its parents'
- Dr Arthur was acquitted
- Some claimed that the decision in R v Arthur was flawed

# Re J ( A minor) [1990] 3 All ER 930

- Taylor LJ made the important point that, in deciding **whether or not treatment was in a patient's best interests**, it should be remembered that “even severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable”

# Re J ( A minor) [1990] 3 All ER 930

- “I consider that the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether **in all the circumstances such a life would be so afflicted as to be intolerable to that child.** The test **should not** be whether the life would be intolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable.”

# Seminal Case

- The case of Airedale NHS Trust v Bland [1993] was the first case that the English courts were required to consider **the lawful discontinuation of life sustaining treatment concerning an adult patient**
- In Bland, the court **decided in favour of discontinuing artificial hydration and nutrition**

# Airedale NHS Trust v Bland [1993]

## AC 789

- Tony Bland, an 18 year-old football fan, was one of the victims of the Hillsborough disaster in 1989
- He suffered crushed ribs and punctured lungs; the deprivation of oxygen to his brain caused severe damage.
- He was in PVS only relied on PEG feeding for nutritional and hydration support for three years already
- The parents and medical team applied to the High Court for an order to allow lawful withdrawal of the feeding tube

# Airedale NHS Trust v Bland [1993]

## AC 789

- The judges of the HC considered that being kept alive in a PVS condition was no benefit at all to patient and his family and the use of life-sustenance measures **was not in the best interests**
- The ruling implied that tube feeding was **considered futile** for Tony
- Tony died nine days after the PEG was withdrawn

# Reasoning for incompetent patient

- Withdrawal of treatment ?
- What is medical treatment ?
- Best interest ?
- Futility ?



# Withdrawal of treatment

- In common law, a distinction is drawn between **acts and omissions** with the latter tending to be seen as less culpable
- In Bland it was accepted that the withdrawal of ANH is an omission to treat, it is not an act for satisfying the actus reus of murder

- Lord Goff endorsed **the distinction between** an act and omission
- ..The doctor's conduct in discontinuing life support can properly categorized as an omission...discontinuation of life support is, for present purposes, **no different from not initiating life support in the first place**...the doctor is simply allowing his patient to die in a sense that he is **desisting from taking a step** which might, in certain circumstances, prevent his patient from dying as a result of **his pre-existing condition**

- An omission to treat would be unlawful only if doctors **had a duty to treat**
- In Bland, since there was no hope of recovery, omitting to provide ANH would not be a breach of duty

- The distinction can be supported in terms of causation
- An omission cannot cause death; death is caused by the underlying medical condition

- Beauchamp and Childress (2009) commented that the distinction between killing and letting die suffers from vagueness and moral confusion.
- The language of killing is so thoroughly confusing- causally, legally and morally- that it can provide little if any help in discussion of assistance in dying

# Common sense approach

- Whether stopping a respirator is an act of killing or a decision to let nature take its cause.  
**Common sense suggests it is the latter**
- Stopping the respirator is not a positive act of killing the patient, but a decision not to strive any longer to save him

# Criticism

- Critics against this view argues whether the killing is good or not – not focus whether there was an act or an omission
- It is the outcome that matters, not how the outcome was produced

# Treatment of severely disabled children

- UK :Nuffield Council ( 2007) : summary of treatment of severely disabled children
- An argument can be made that some disabilities are so severe that the sufferer should not even be regarded as a person, e.g. anencephalic infants



# Legal principle

- It is not permissible to do an act that intentionally cause the death of the patient
- But a doctor may decline to provide treatment to a patient **if** that is in a patient's best interests and it is in accordance with established medical practice

# Re M [2017] EWCOP 19

- M was in minimal conscious state and M's family and an independent expert all believed it would be appropriate to withdraw assisted nutrition and hydration
- Yet, even without doing so, M would die

# Re M [2017] EWCOP 19

- There was a strong presumption it was someone's best interest to remain alive
- The court looked at her best interest in broad sense, decided it was not her best interest to be kept alive
- Particular weight was placed on whether M herself, if she were able to express a view, would regard her future life as worthwhile

# Re M [2017] EWCOP 19

- If the decision to withdraw treatment was in line with the professional guidance and the views of medical professionals and family members, there was no need to bring the matter to court for approval
- Only if there was disagreement, then the court should be involved

# Great Ormond Street Hospital v Yates & Gard [2017]EWHC 927 (Fam)

- Extensive litigation involving an eight-month-old baby, Charlie Gard, which attracted worldwide publicity
- Charlie, being affected by a genetic condition and developed severe brain injury
- Everyone agreed his current state of life was not worth sustaining

# Great Ormond Street Hospital v Yates & Gard [2017]EWHC 927 (Fam)

- The Great Ormond Street Hospital sought a declaration to authorize the withdrawal of ventilation and provision of palliative care only
- The parents disagreed and wanted Charlie to travel overseas to be given a novel form of treatment known as nucleoside therapy, which the hospital believed to be inappropriate
- The hospital therefore sought an order it was lawful that Charlie not receive that therapy

# Charlie Gard: The story of his parents' legal fight

🕒 27 July 2017

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Charlie Gard case



Charlie's parents had raised more than £1.3m to take him to the US for treatment

# Legal principle

- The court had to base its decision on what was in **Charlie's best interests**
- The views of his parents carried weight, but it was for the court to make final assessments
- Charlie's current quality of life was not worth sustaining
- The proposed treatment had no chance of success and taking Charlie overseas would only cause him pain
- It was not in his best interests to travel and it would be lawful to withdraw treatment



# Implications of Bland

- Bland establishes that it **can be lawful to withdrawal LST from patients who are diagnosed as being a PVS**
- A significant issue was that Tony Bland had lost sentience irrevocably, therefore, according to the majority of the House, Tony has **no further interest to protect**, or promote. This runs counter to the belief that full moral status should be accorded to all living persons

# Implications of Bland

The House of Lords was not insensitive to the potential dangers of withdrawal of treatment from invulnerable unconscious patients. **Several safeguards** were identified:

- Efforts to rehabilitate should be made for at least six months
- Irreversible PVS should be diagnosed before 12 months and no decisions to withhold or withdrawal treatment should be made before that time
- Diagnosis is to be confirmed by **two independent** doctors
- Great weight should be given to **the wishes of the family**; and
- A court declaration would be necessary prior to withdrawal of treatment at least until a body or precedent had been built up

“...the answer which will be given in relation to a particular problem dealing with a particular set of circumstances, is a much better answer than an answer given in advance. The **difficulty** in this area is that there are conflicting principles involved. The principles of law are clearly established, but **how you apply** those principles to particular facts is often **very difficult to anticipate**”

Lord Woolf MR

*R v Portsmouth Hospital NHS Trust ex p Glass* [1999]2 FLR 905

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Thank You  
Q & A