PICU and the High Court

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Topics

- Legal framework
- Withdrawal/withholding LST
- Novel treatment
- Practical aspects of court proceedings

Legal framework

- Child who is not competent cannot give or refuse consent to medical treatment
- Consent must be obtained from one or both parents, or another person with parental responsibility
- If parents disagree with doctors, or with each other, or only person with PR is local authority.....  Court

Best interests

- The **only** test is whether the proposed course of action is in the child's best interests

- **NOT** whether it may cause significant harm, whether the parents' views are reasonable, or anything else

What is ‘best interests’?

- S.1 Children Act 1989 says the court must have regard to:

(a) the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding);

(b) his physical, emotional and educational needs;

(c) the likely effect on him of any change in his circumstances;

(d) his age, sex, background and any characteristics of his which the court considers relevant;

(e) any harm which he has suffered or is at risk of suffering;

(f) how capable each of his parents, and any other person in relation to whom the court considers the question to be relevant, is of meeting his needs;

(g) the range of powers available to the court.

Judicial guidance

Decision-makers should:

- Look at welfare in the widest sense, not just medical but social and psychological;
- Consider the nature of the medical treatment in question, what it involves and its prospects of success;
- Consider what the outcome of that treatment for the patient is likely to be
- Try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.

Aintree University Hospital NHS Foundation Trust v James [2013] UKSC

Judicial guidance (2)

- Best interests include medical, emotional, sensory (pain, pleasure and suffering) and the instinct to survive
- Considerable weight/very strong presumption in favour of prolonging life
- Views of parents must be considered, particularly where parents spend a lot of time with their child
- No extra tests like ‘intolerability’ or ‘unbearable suffering’

An NHS Trust v MB [2006] EWHC 507 (Fam)

Withholding/withdrawal

- RCPCH guidance '**Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children; a Framework for Practice'**
  1) When life is limited in quantity;
  2) When life is limited in quality;
  3) Informed competent refusal of treatment.

The Guidance is exactly that. It is not binding on a court and has no legal force. Nevertheless, in reality it forms the backdrop against which multidisciplinary medical teams conduct their assessments when they address what is described in the Guidance as "the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child".

Re A (A Child) [2016] EWCA Civ 759

Past cases

- Common applications:
  - No CPR
  - Withdrawal of invasive ventilation
  - No move to invasive ventilation
- Majority of cases result in agreement between the doctors, the guardian and the court
- Some exceptions…

An NHS Trust v MB [2006] EWHC 507 (Fam)

- SMA, 18 months old, ventilated
- Declaration permitting withdrawal refused despite unanimous view of all treating doctors, 4 independent experts and the guardian
- Reasoning: '*helpless and sad life'* but did have normal cognition and relationship of value to him with his family
- But no CPR or other treatments required due to deterioration

I know that the family members believe that by surrounding Reyhan with infinite love and first-class care, they can protect him from many of the worst aspects of his condition, and I accept without question that they mean what they say. However, putting Reyhan first, I cannot in the end take the same view. The family members wish to continue on this journey, believing that they can carry Reyhan on their shoulders and put him down only when the time is right. This in my view overlooks the reality. If Reyhan is to continue on the journey of long-term ventilation, he will have to walk every step of the way himself. Others can surround and encourage him, but it is Reyhan, and Reyhan alone, who will have to bear the burdens while experiencing little if any pleasure. And the road that he would be asked to walk is one that would grow steeper with every passing week.

An NHS Foundation Trust v R (Child) & Ors [2013] EWHC 2340 (Fam)

Recent cases

- Isaiah Haastrup
  - Severe brain damage
  - No objective evidence of conscious awareness
  - No prospect of recovery
- Alfie Evans
  - Reflexive responses only
  - Treatment futile

Common themes and issues

- Assessment of consciousness
- Experience of pain/pleasure?
- When does continuing ventilation become the wrong thing to do? Why now?
- LTV criteria and transparency of decisions
- What happens after withdrawal

Novel treatment

- Simms v An NHS Trust [2002] EWHC 2734 (Fam)
  - possible prolongation of life (not recovery) where current QoL was ok
  - '*In a finely balanced case I should give the views of the parents and the effect upon them of refusal great weight in the wider considerations of the best interests test which the court has to apply to each patient*.'

Gard

- Likely to have awareness of pain
- "*Charlie's parents accept that his current quality of life is not good and that they would not seek that it should be sustained without hope of improvement*"
- Significant brain damage - Dr I: "*I think to a large extent it is irreversible, but I cannot say it is completely irreversible…..the chances of meaningful brain recovery would be small, which he agreed he could not distinguish from vanishingly small…..*"

Practical aspects

- Alternatives to court
  - Medication, Clinical Ethics Committee, round table meeting
  - ***An NHS Trust v S & L (A Child) (Witholding Life Sustaining Invasive Treatment***) [2017] EWHC 3619 (Fam)

Sample agreement - extracts

- Where there is doubt as to reversibility, presumption in favour of mechanical invasive ventilation for a time limited trial of around 48 hours unless X improves and is successfully extubated earlier
- Where there is a slow deterioration of baseline respiratory function which has not improved from baseline without any signs of additional process e.g. secondary infection then intubation and ventilation is likely to be inappropriate. Where it is not possible to rule out an additional process then a period of time limited intubation and mechanical ventilation is a reasonable strategy to help determine reversibility. Subject always to an evaluation of the rate of improvement or deterioration in X's respiratory function and the degree of pleasure and/or discomfort X is displaying over time.
- X will move to a palliative care pathway if there is no reasonable expectation of her improving to discharge from PICU.

Practical aspects (2)

- Anonymity/media coverage

- Evidence
  - Honest
  - Comprehensive
  - Day-to-day knowledge
  - Daily records

Resources

- Medical Mediation Foundation – www.medicalmediation.org.uk Twitter: @medmediation

- All the cases are available (free) on www.bailii.org