

Transforming children's rights? Dilemmas,  
challenges and implementation

**Challenges and dilemmas in Medical Law: Is the  
best interests test for the care of children fit for  
purpose?**

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# Why now?

- 30<sup>th</sup> anniversary of UN Convention on the Rights of the Child (UNCRC) [emerged 1989; ratified by the UK 1991]
- Recent high profile cases have shone a spotlight on the care of critically ill children and the best interests test: Aysha King, Charlie Gard, Alfie Evans
- Speaks to key questions posed by this conference...



# Key questions posed by this conference

- What are and should be the **roles of key stakeholders**: the state, parents, children, medical professionals?
- What challenges arise when **translating the law into meaningful action** on the ground?
- What are the **potential solutions**?

Taken together, with commitment to learning across sectors and across the UK, this leads us to ask:

**What can we learn from contemporary challenges and dilemmas in medical law relating to the best interests test for the care of critically ill children?**

# Points to cover today

- What is the best interests test in the context of critically ill children?
- How has this been challenged by cases involving critically ill children, such as Charlie Guard?
- What broader lessons emerge from this? Where next?

# What is the best interests test? (1)

## United Nations Convention on the Rights of the Child (CRC) 1989 [ratified by UK in 1991], Article 3

1. In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, **the best interests of the child shall be a primary consideration.**

2. States Parties undertake to ensure the child such protection and care as is necessary for his or her well-being, **taking into account the rights and duties of his or her parents, legal guardians, or other individuals legally responsible for him or her,** and, to this end, shall take all appropriate legislative and administrative measures.

- Establishes the relationship between best interests of the child and rights and duties of parents/guardians
- Specific provisions for health, as there are for education

# What is the best interests test? (2)

**Children Act 1989:** ‘the child’s welfare shall be the court’s paramount consideration’

**Wyatt v Portsmouth NHS Trust [2000] 1 FLR 554, para 38:**

*In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child’s best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the child. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. **The term “best interests” encompasses medical, emotional, and all other welfare issues.***

# What is the best interests test? (3)

**An NHS Trust v. MB (A Child represented by CAFCASS as Guardian ad Litem) [2006]**

Best interests are used in the **widest sense** and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, **medical, emotional, sensory** (pleasure, pain and suffering) and **instinctive** (the human instinct to survive) considerations.



# What is the best interests test? (4)

**An NHS Trust v. MB (A Child represented by CAFCASS as Guardian ad Litem) [2006]**

**The views and opinions of both the doctors and the parents must be carefully considered.** Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. **Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship [emphasis added]**





# Assessing best interests: GMC guidance, 0-18 years

**12.** An assessment of best interests will include what is clinically indicated in a particular case. You should also consider:

- the views of the child or young person, so far as they can express them, including any previously expressed preferences
- the views of parents
- the views of others close to the child or young person
- the cultural, religious or other beliefs and values of the child or parents
- the views of other healthcare professionals involved in providing care to the child or young person, and of any other professionals who have an interest in their welfare
- which choice, if there is more than one, will least restrict the child or young person's future options.

**13.** This list is not exhaustive. The weight you attach to each point will depend on the circumstances, and you should consider any other relevant information. You should not make unjustified assumptions about a child or young person's best interests based on irrelevant or discriminatory factors, such as their behaviour, appearance or disability.

# Challenges to the best interest test: Charlie Gard (1)

- Charlie was born 4 August 2016
- Admitted to GOSH 11 October 2016 and found to have a rare genetic condition (MDDS)
- No proven treatment but theoretical possibility nucleoside therapy (NT) might lead to improvement
- GOSH considered NT but by the time ethical permission was granted considered this to be contrary to Charlie's best interests
- Parents raised £1.3M and located US neurologist who was willing to provide NT
- Case referred to the High Court on 3 March 2017



# Challenges to the best interest test: Charlie Gard (2)

## High Court

4 declarations sought by GOSH that:

- Charlie lacked capacity
- That it was in his best interests for artificial ventilation to be withdrawn
- That palliative care should be administered
- That it was not in Charlie's best interests to undergo NT

Guardian appointed to represent Charlie



# Challenges to the best interest test: Charlie Gard (3)

**High Court** (Frances J) granted declarations. Upheld at three levels of appeal by

- **Court of Appeal** – upheld [family argued that ‘significant harm’ test should apply]
- **Supreme Court** – declined to grant permission to appeal
- **European Court of Human Rights** – application inadmissible [stay granted while under consideration]

**High Court** – agreed to review new evidence from US Dr Mirano – but after examination MRI scan indicates it was too late to provide NT

# Challenges to the best interest test: Charlie Gard (4)

Key elements of the case:

- Charlie's parents did not have access to legal aid – lawyers represented them pro bono
- High profile nature – reports from GOSH of threats to staff; mixed reporting of '*pioneering treatment*'
- The role of mediation was flagged by Francis J
- Argument for 'significant harm' test was rejected – limitation of scope of parental rights

# Lessons learned...

Role of legal mechanisms – international law, domestic law and how this plays out in the Courts as a backstop

BUT

Also highlights the **limits of the law**:

- Impact of **delay**, demands on **resources** of all parties, **polarisation of views** (Austin, 2018; Nuffield, 2019)
- The ‘lose, lose, lose’ situation (Meller and Barclay, 2011 describing *Wyatt*; cited in Huxtable, 2018)
- Spotlight on the legislation and court room – but misses what goes before?

**Taken together suggests legal mechanisms – in and of themselves – are not enough**

# Why do disagreements develop?

‘The reasons why disagreements develop are wide ranging, but common themes include: **communication** issues; **differing perspectives, beliefs and values** that lead to disagreements on, for example, what kind of risks justifiably could be taken; feelings of **powerlessness** for both parents and staff; and **delays** in seeking resolution interventions.’

Nuffield Council on Bioethics, April 2019



# Where next?

- More law? Substantial harm test
- Realising advocacy powers of parents - advice and support for families, inc Legal Aid (Francis J, para 130)
- Medical mediation – funded within NHS Trusts
- Clinical Ethics Committees (Huxtable, 2018; Austin; 2018, Nuffield, 2019)
- Support for child’s voice – role of Guardian (as highlighted by Lady Hale in Gard) or (in other cases) for ‘the child capable of forming his or her own views’ (Article 12 UNCRC)?



# Closing remarks

- Preceding discussion highlights both **benefits and limits** of law
- Shifts discussion from **text to context**
- **Synergies** with discussions today?



# References:

Austin L, *Literature review: UK processes for resolution of disagreements about the care of critically ill children*, September 2018, <http://nuffieldbioethics.org/wp-content/uploads/Austin-L-2018-UK-processes-for-resolution-of-disagreements-in-care-of-critically-ill-children.pdf>

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Huxtable R, *Clinic, courtroom or (specialist) committee: in the best interests of the critically ill child?* *Journal of Medical Ethics* 2018;44:471-475.

Nuffield Council on Bioethics, *Briefing Note: Disagreements in the care of critically ill children*, April 2019, <http://nuffieldbioethics.org/project/briefing-notes/disagreements-care-critically-ill-children>

*GOSH v Yates, Gard and Gard [2017] EWHC 972*

*Yates and Gard v GOSH [2017] EWCA Civ 410*

*In the matter of Charlie Gard [2017] UKSC 2018*

