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## THE CHILD AND MEDICAL TREATMENT: THE CHANCE TO LIVE, OR TO DIE WITH DIGNITY?

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What happens when doctors and parents cannot agree on whether a child should be given experimental medical treatment? Why there is any question mark over a parent's right to decide if medical treatment for their child continues?

From the parents of Ashya King who successfully secured proton beam therapy for their son to the despair surrounding baby Charlie Gard and his life-limiting genetic disorder: how does the court make decisions that can potentially prolong life or bring about the death of a child?

All of these questions encapsulate fierce conflicts between different standpoints. Ethics may help us to resolve them, but the law may be too blunt a sword to capture the nuances of these situations.

Some of these contentious and complex issues are to be discussed in conversation between Gresham Professor of Law Jo Delahunty and Dr Imogen Goold of St Anne's College Oxford.

This handout provides you with an introduction to the relevant debate, with suggestions for further reading if you would like to learn more about an aspect of this lecture. It is not in my usual format with narrative argument and opinion because tonight lecture presents a discussion between Dr Goold and myself, and one knows not what direction it will take as we explore the legal and ethical dilemmas involved in these heart-breaking cases. This handout has been prepared by Dr Goold and me, with the intention that it provide food for thought so you may follow and participate in the exchange between us.

### **Best interests and/or consent?**

Neither the nature nor the application of the concept of 'best interests' are free of contention where children's medical treatment is concerned. The law's treatment of children is far more paternalistic and welfare-based than that of adults, hence the focus on the child's best interests, objectively assessed by the court, rather than on their rights or wishes or that of their parents.

To find out more about how the child's welfare is considered, the following cases will be of interest:

#### Gard v Great Ormond Street Hospital [2017] EWCA Civ 410

Best interests are used both as the threshold test for intervention *and* the test for allowing medical treatment.

#### Re Jake [2015] EWHC 2442

Parents views as to what is in their child's best interests will be given weight (even if they lack mental capacity).

#### Re C (baby: withdrawal of medical treatment) [2015] EWHC 2920 (Fam)

Best interests evaluation is a holistic exercise that takes into account doctors' and parents' views, as well as the child's idea of quality of life.

*"I particularly affirm that the ultimate determination of the best interests is made by the Court, and not by the parents or the doctors, though their views are to be carefully considered. Further, although the views of doctors on medical issues will be a prominent feature in a case where a child is so medically dependent, the best interests evaluation considers all matters and not only medical ones. Lastly, I emphasise that in considering quality of life, the Court looks from the child's perspective and not from the perspective of others more fortunate"* – per Mr Justice Peter Jackson

#### Kirklees Council v RE [2014] EWHC 3182 (Fam)



Two kinds of cases where withholding treatment from sick children may be appropriate: where treatment is futile or unreasonably arduous

*“27. The ‘no chance’ situation is one where the child has ‘such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering’. In such a situation where treatment delays death but neither improves life quality or potential, continued treatment is defined as being ‘futile and burdensome and not in the best interests of the patient’.*

*28. The ‘no purpose’ situation is one where, although the patient ‘may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it’. It adds that, in such cases, ‘continuing treatment might leave the child in a worse condition than already exists with the likelihood of further deterioration leading to an impossibly poor life’.” – Per Mr Justice Moor*

#### Re G (Children) [2012] EWCA Civ 1233

Best interest’s evaluation can take into account the child’s relationships

*“As Herring and Foster comment, relationships are central to our sense and understanding of ourselves. Our characters and understandings of ourselves from the earliest days are charted by reference to our relationships with others. It is only by considering the child’s network of relationships that their well-being can be properly considered. So a child’s relationships, both within and without the family, are always relevant to the child’s interests; often they will be determinative.” – Lord Justice Munby*

#### Gillick v. West Norfolk and Wisbech Area Health Authority [1986] AC 112

This case gave its name to a concept now known as ‘Gillick Competence’: a term used to decide if a child (under the age of 16) is able to consent to his or her own medical treatment without the need for parental permission or knowledge if they are believed to have enough intelligence, competence and understanding to fully appreciate what’s involved in their treatment. Like adults, young people (aged 16 or 17) are, presumed to have sufficient capacity to decide their own medical treatment unless there is sufficient evidence to show otherwise.

#### **Medical expertise: paternalism or respect?**

Doctors have expertise in assessing the best therapeutic treatment option for a patient. However, in a family there is often much more at stake than calculating how best to maximise a patient’s health in terms of medical management: religious beliefs, life values, relationships, and the patient’s sense of self, to name a few.

Balancing these factors is complicated further by the patient’s youth, in the case of children’s medical treatment. The line between paternalism and respect for a doctor’s expertise and parental choice is particularly nuanced where the conflict is between medical and familial value-based choices; e.g. a decision about which risks are worth certain dis-benefits.

It is essential to remember when considering these conflicts that both sides are desperately trying to do what they think is best for the vulnerable child at the heart of the dispute; by the time the case gets to court, no-one is ambivalent.

To find out more about how the child’s welfare is considered, the following cases and academic works will be of interest:

#### An NHS Trust v W [2015] EWHC 2778 (Fam)

Where the medical opinion is divided or unclear, it may well be that the views of the parents will tip the balance in favour of ordering treatment.

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

Medical expertise on a child’s expected deterioration will not always outweigh a parent’s view that a child still has some benefits from life

Mr Justice Holman placed much weight on the fact that, although he could communicate in a very limited way with them, the evidence suggested that MB had pleasure from being with his parents; *“the single most important source of pleasure and emotion to a small child: his relationship with his parents and family”*

#### See Dr Giles Birchley work on clinical practice<sup>1</sup>

Clinicians tend to allow a wide degree of latitude to parents’ choice and continue treatment for the sake of families, but tend to stop or resist at the point at which it is harmful

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<sup>1</sup> Dr Giles Birchley’ 2005 Clinical Ethics committee’s advice when deciding for critically ill infants: An Answer to a problem or a problem to an answer?’ University of Bristol [www.bris.ac.uk/social-community-medicine/people/giles-m-birchley/pub/44171652](http://www.bris.ac.uk/social-community-medicine/people/giles-m-birchley/pub/44171652)



Birchley's work suggests clinicians will do things that may be a little beyond 'best interests' but tend to refuse when it is considered ethically and medically adverse to the patient's best interests looking through the medical lens at the options for them. Professor Jo Bridgeman argues that we should understand conflicts between medical teams and parents as instances of professional medical conscience, where medical teams come to court essentially when they can no longer acquiesce to parental wishes.

This theory is given expression by this comment from an anonymous Great Ormond Street Hospital staff member on the impact of the Charlie Gard conflict as reported in, *The Guardian*, 4<sup>th</sup> August 2017.

*"it's our job, our legal and moral obligation, to stand up for him and say when we think that enough is enough...we did everything that we could, even though we thought he should be allowed to slip away in his parents' arms, peacefully, loved. We didn't do this for Charlie. We didn't even do it for his mum and dad. Recently, we did this for Donald Trump and the pope, who suddenly knew more about mitochondrial diseases than our expert consultants. And we did it for the keyboard warriors who thought it was OK to write about the 'evil' medical staff at Great Ormond Street, even though we were still there next to Charlie, caring for him as best we could, as we always had. We did it with every fibre of our being telling us that it was wrong, we should stop. But we couldn't."*

### **Parents' Input: rights or responsibilities**

Against the objective assessment of the child's best medical treatment plan presented by the medical team one has the family. Whilst a doctor makes a recommendation based on a patient's needs the reality is that they don't have to live with the consequences of that plan 24/7 for the lifetime of the child or the family. Moreover, they come to the case as outsiders for a fixed point and for a defined reason. Parents know their child better than anyone else. They are the custodians of the history of the child as a living breathing, loved and loving anchor of the family. Reflect on their:

- Parental expertise
- Knowledge their child
- Responsibility for their child

And indeed, part of the argument in *Gard* and other cases where parents and the medical team were in conflict is that there should be 'both priority and protection to the privileged position of a parent'. Much of the public discourse around the case centred on the assertion of parental 'rights' and the view that parents should final arbiters of a child's care.

It seems a self-evident presumption that parents should decide what is best for their child until one factors in that the child is not the chattel of a parent. The child has rights of its own and sometimes, when those rights conflict with what a parent wants for them, however deep the well of heartfelt love from which the parental wishes spring, the child's best interests, objectively assessed by the court who hears argument from the parents, the hospitals and on behalf of the child, will decide outcome not the parents views. In law, the parent's views as to what is in the child's best interests is not a trump card; the child's welfare is of paramount importance.

### **Gillick v. West Norfolk and Wisbech Area Health Authority [1986] AC 112 per Lord Fraser**

Consider the issue of blood transfusion raised in Jehovah witness cases for one such example. The transfusion offers the chance to the child to live, the refusal will lead to their death. When the child is not old enough to choose life or death themselves should the right to live be removed from the by their parents?

*"Parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child and they are justified only in so far as they enable the parent to perform his duties towards the child, and towards other children in the family."* –

Per Lord Fraser

*"[W]hen a court has before it a question as to the care and upbringing of a child it must treat the welfare of the child as the paramount consideration in determining the order to be made. There is here a principle which limits and governs the exercise of parental rights of custody, care and control. It is a principle perfectly consistent with the law's recognition of the parent as the natural guardian of the child: but it is also a warning that parental right must be exercised in accordance with the welfare principle and can be challenged, even overridden, if it be not."* –

Per Lord Scarman<sup>2</sup>

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<sup>2</sup> Gillick v. West Norfolk and Wisbech Area Health Authority [1986] AC 112



The law has decided that it is not enough simply to say that being a parent in and of itself creates such a privilege to exclusively determine the outcome for their child. In the majority of cases dispute as to outcome for the patient is resolved by discussion and debate between the family and medical, team precisely because:

- The law recognises the importance of respecting parental authority because very often this will actually be the approach that protects a child's welfare
- Parents know their child intimately
- Parents are best placed to understand the familial, societal, religious balance they have created in the family which their child at its core
- They can situate the child's needs in that family unit better than anyone else
- Parents are deeply committed to achieving the best for their child not just in this moment of decision but for their lifetime; however long or short that is

### Re T [1997] 2 FCR 363

T was ill for many years, and although their doctors said a liver transplant was necessary, T's parents argued that T was exhausted of interventions. The court accepted that parental care would be essential to T's recovery, and consequently without parental support, a liver transplant would harm T; the court found in favour of the parents [N.B. the parents changed their minds afterwards, the operation went ahead, and T recovered]

*"Some of the objections of the mother, such as the difficulty of the operation itself, turned out ... to be less important than the mother believed. Underlying those less important objections of the mother as to the benefits to her son of the major invasive surgery and post-operative treatment, the dangers of failure long term as well as short term, the possibility of the need for further transplants, the likely length of life and the impact upon her son of all these concerns... The mother and child are one for the purposes of this unusual case ... the welfare of the child depends upon his mother."*

When one factors in the time and environment in which such profound decisions are to be made consider that

- Parents need 'space' in which to make many decisions
- They need to feel they have freedom in which to work out the balance
- They need to feel supported and respected rather than policed
- In exercising autonomy, parents develop autonomy

But also, it is impossible to police parenting nor should we as a society do so.

*"Society must be willing to tolerate very diverse standards of parenting, including the eccentric, the barely adequate and the inconsistent. It follows too that children will inevitably have both very different experiences of parenting and very unequal consequences flowing from it. It means that some children will experience disadvantage and harm, while others flourish in atmospheres of loving security and emotional stability. These are the consequences of our fallible humanity and it is not the provenance of the state to spare children all the consequences of defective parenting. In any event, it simply could not be done."* – Mr Justice Hedley<sup>3</sup>

The law intervenes only when it is essential to do so in to protect the child from avoidable harm: hence why we have child protection laws that are enforced in the family court

### The court's role: meddling or necessary?

Courts / State have long held responsibility for the vulnerable in society. Law often operates to protect those who cannot protect themselves

- Children
- Mentally incompetent
- Incapacitated

But there is, then, a tension between protecting difference in values and parenting approach and giving parents scope to parent, trusting parents.

How can we accommodate plurality of views on what is best for a child in a democratic, open, society that values privacy and respects autonomy, while also being committed to protecting those who cannot protect themselves?

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<sup>3</sup> RE L (Care; Threshold criteria) 2007 1 FLR 2050



The state steps in to regulate the exercise of that responsibility in the interests of children and society as a whole. But 'the child is not the child of the state' and it is important in a free society that parents should be allowed a large measure of autonomy in the way in which they discharge their parental responsibilities.

That question poses fundamental questions about the right boundary between state interventions in the familial sphere. How far should the state be permitted to involve itself in the private sphere for the sake of those who cannot speak for themselves? How do we protect that vulnerable party, the child, as a community? Which values are at stake and how we rank them?

The state has a number of avenues to address concerns about a child's welfare. The State has a legitimate role to play in seeking to regulate parental decisions when to fail to do so would expose the child to harm or the risk of avoidable significant harm. That is why we have care proceedings via the Children Act 1989. It's why the High Court's Inherent jurisdiction can be invoked when the child's welfare demands it and where their needs cannot be adjudicated upon in any other legal framework.

Court can, as confirmed in *Gard*, resolve disputes where a child's welfare is engaged.

#### Great Ormond Street Hospital v Yates [2017]

*"Although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests."* – Per Francis J

*"If best interests were to be relevant touchstone, the distinction between legitimate state action and the discharge of parental responsibility would disappear since any action by parents with which court disagreed could be overruled... if the State can, without the highest of justification, intrude into so private an area of human life as a joint parental decision made about one's child's upbringing, the scope for protection against state interference afforded by our most basic constitutional values, as well as by Article 8 ECHR, is considerably eroded."* – Richard Gordon, QC, counsel for appellants

Clearly Article 8 rights to a private family life apply in *Gard* but, according to Strasbourg jurisprudence, any conflict between the rights of parent and child under Article 8 ought to be resolved in favour of the child

English law has long recognised that the child has an existence and legal right distinct from its parents. In Children's Act cases they have their own guardian and lawyer appointed, as they do in Best Interest cases that need the courts resolution: why is this? *It is 'because children are not just the passive recipients of other people's concerns for their best interest-they are moral actors in their own right, with a point of view of their own, which should be heard'*<sup>4</sup>

Per Baroness Hale

#### **When to intervene?**

Only a very very small percentage of cases that involve complex medical treatment decision for a child ever come to court and that is because the ethos is there is no need to intervene as long as parents are acting within 'the broad spectrum of reasonable and lawful approaches to their child's welfare'. But when respectful and informed dialogue cannot receive can impasse, then the courts get involved to make a decision on behalf of the child: seeking to resolve the dispute between parent and hospital. How do they weigh the factors on each side on each side of the scales so as to decide what should happen to the child?

#### **The balance: the debate between a best interest's decision and one based on harm**

##### The current approach:

*"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."* – Wyatt v Portsmouth NHS Trust [2005] EWHC 117

In the Charlie Gard, Alfie Evans and Isaiah Hastrup litigation

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<sup>4</sup> Baroness Hale 'Making Children's Rights Real' 2006 Inaugural lecture of the Children's Law Centre



- The courts have made clear that they have the power to make medical decisions for children at the point that child's welfare is engaged
- All courts involved in both cases affirmed the orthodox position that the threshold for judicial intervention in disputes about medical care of children is the welfare of the child often referred to as the 'best interests' approach (referring to both the threshold and the test applied to determine what should be done).
- In all three cases, the court refused to accede to the wishes of the parents, holding that it was not each child's best interests that they continue to receive life-sustaining care, nor to travel to be given an experimental treatment. Consequently, withdrawal of treatment was authorised in each case being in the child's best interests

### The alternative view

In the aftermath of the Charlie Gard case Charlie's parents sought to put their experiences to positive effect by advancing a change in the 'best interest' approach.

Charlie's Law proposes three core changes to the current system, including a shift to 'harm threshold', meaning that courts cannot intervene to make decisions on behalf of a child unless the parents' decision poses a serious risk that the child will suffer significant harm as a result.

Thus far, these efforts have been unsuccessful, but as of October 2018, the Parliamentary Under-Secretary of State for the Department of Health and Social Security had agreed to work on possible future

So: do we have the balance right? Consider

#### Why a best interests approach?

- Balancing exercise between all points of view, including the child's.
- Focus on all aspects in the round

#### Why a harm approach?

- Reflects current practice
- Medics don't come to the court in absence of concern about harm
- Protects parental decisions from over-control
- Promotes respect for value difference

### What objections are there to a Harm Threshold?

It is said it will make no practical difference. It is not necessary as the law (and clinical practice) already respect parental authority<sup>5</sup>. It doesn't resolve hard cases any better than best interests. It undermines shared decision-making by giving parents trumping rights. One of the key tenets of clinical decision-making in these cases is to work *with* parents to build consensus on the best way forward for the child

### But why we should consider a move to a harm threshold despite these concerns?

Because it reflects current practice in reality. The court already deals with cases where the parent's wishes have actually already crossed the threshold. The work by Dr Giles Birchley of Bristol University and others on clinical practice reveal that clinicians

- allow a wide degree of latitude to parents' choice
- continue treatment for the sake of families
- tend to stop / resist at the point at which it is harmful
- because at that point their own duties under the Hippocratic Oath and their medical conscience require them to say 'no'.

Would not a shift to harm threshold would better reflect that actual point at which medical teams request intervention?

What the shift in test to 'harm' might do is to trigger the right to funded legal representation for the parents, as parents are entitled to in public law care proceedings when it is alleged they have caused harm to their child and

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<sup>5</sup> Birchley makes the important point, as others have, that clinicians already give considerable respect to parental wishes



the state seeks to intervene to scrutinise their care and make decisions for the child which run counter the parents' wishes

As a practitioner I cannot overstate the important of their being a level legal playing field in court. The Hospitals will be legally represented, the child will be (funded under legal aid); but the parents have no such right unless they can pay for it. How does that help in a court room scenario when the matter has only been put before the court because the parties have gone past the point of agreement? Court is stressful. It is not a forum most parents would have encountered before. The legal process is daunting for those that know it oftentimes, how much worse for a parent coming to court in a situation of extremis in law and emotion?

*It is not for judges to make political points and I do not now seek to do so. However, it does seem to me that when parliament changed the law in relation to legal aid and significantly restricted the availability of legal aid, yet continued to make legal aid available in care cases where the state is seeking orders against parents, it cannot have intended that parents in the position that these parents have been in should have no access to legal advice or representation. To most like-minded people, a National Health Service trust is as much an arm of the state as is a local authority. I can think of few more profound cases than ones where a trust is applying to the court for a declaration that a life-support machine should be switched off in respect of a child.*

Per Francis J in the Charlie Gard case (2017 EWHC 2909)

As a society, we need to think about why many decisions relating to medical care are ones where there can be reasonable disagreement and where both courts and medical practitioners are prepared to allow for parents to make choices that others might not think are optimal. This is because many of these choices are not *medical*. The parents involved don't need extra information. They have come to the point when the parents are making choices about *value*.

A decision about which risks are worth certain dis-benefits is not purely a medical question.

Is a small chance of recovery worth the unpleasantness of the treatment is a *value* decision?

When we see decisions at the end of life in this way, we can then wonder who is best placed to answer questions of this kind. Why would we think someone other than a parent can know best on these matters? There are different ways to understand value and what makes lives go well.

We can and do reasonably disagree on this.

But the arguments in favour of change have their down side. Move to a harm threshold may entail shifting away from an approach that emphasises deciding what is *best for* a child, towards one that explicitly requires the court to demonstrate that it has authority *because* a parental decision will place that child at risk of harm. Katie Gollop QC and Sarah Pope have written about this "They identify the danger that it would turn an inquisitorial process, where everyone assists the court in its task of identifying where the child's best interests lie, into an adversarial one. Once a conflict arose, rather than working towards consensus-building as is currently the case, the hospital (and lawyers) would need to begin building the case for overriding the wishes of parents by establishing that their wishes posed a risk of significant harm to the child which would of itself have a divisive and stigmatising effect. Positions would harden unnecessarily, and dialogue would be more difficult. Mediation would have less, not more, chance of success.

Would that introduce a 'fault' component which the dissenting parent would have to bear if the court decision goes against them? Surely that would be intolerable to bear.

But, why should that be our choice to make? If the parents who have been through this soul-destroying process think that that is a price to pay for what they perceive to be a raising of the barrier to interfering with their elected choice for their child: then should we be so paternalistic to say "the consequences of that may be too much for you"?

### **Concluding remarks**

There are, quite simply, no obvious answers to the difficult issues of when and on what basis a child should or should not be treated, or have treatment withdrawn, when the course advanced by the medial team is contrary to

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<sup>6</sup> <http://www.transparencyproject.org.uk/charlie-gard-alfie-evans-and-r-a-child-why-a-medical-treatment-significant-harm-test-would-hinder-not-help/>.



the wishes of the parents. The courts come to decisions that are resolved in favour of the parents and sometimes the medics. The only theme linking the decisions is that the factual basis upon which a court will come to its decision will be a unique as the child's DNA.

Thank you for listening

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