Medical Treatment of Children – Who Decides when Doctors and Parents Disagree?

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Abstract

This article aims to explore the key developments of the best interest test in respect of infants, to reveal that when doctors and parents differ on the proper course of action, the courts have preferred the views of doctors. It is important that the scope of the best interest test be redefined to include non-medical considerations, so that parents do not perceive themselves as being alienated from the decision-making process. This article also expresses the author’s view that since there are benefits and risks in prioritising either the doctors’ opinion or the parents’ wishes, the best solution is to reach a consensus and the least desirable solution is to go to court.

Keywords: Best Interest Test, Infant, Children, Medical Treatment, Neonates, Birth Defects, Parental Wishes, Deference to Medical Opinion

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I. Introduction and Overview of the Issues

Medical advances since the beginning of the new millennium are both welcoming and distressing. They are welcoming in the sense that developments in neonatal intensive care, life support treatment and advanced palliative care have provided medical staffs with the means to prolong life and to alleviate pain even in the most unbearable and futile situations.\(^1\) On the other hand, they are distressing, as they inevitably result in new ethical dilemmas that render decision-making even more challenging.\(^2\) Prior to these medical advancements, most premature babies often died at birth and most babies with major birth defects could not survive for long. This might be seen as the ‘lesser of the two evils’,\(^3\) as God or nature spared traumatised parents from making tough decisions over their children’s fate.\(^4\)

This article will first provide a brief overview of the nature of the dispute between doctors and parents. In part four this author intends to highlight that many of these disputes are resolved without resorting to the legal process. Accordingly, this article focuses on situations where doctors and parents disagree with each other. The article will secondly set out the ‘best interest’ test that has been developed by the courts and will attempt to identify which considerations have proven decisive to outcomes of cases. It is argued that judicial deference to doctors’ opinions remains the norm. There have been relatively few cases where parental wishes took precedence over a doctor’s opinion.

Part three is dedicated to the case of Re A (Children) (Conjoined Twins: Surgical Separation),\(^5\) which has been the subject of extensive discussion. This was a case where the parents argued that the separation of the conjoined twins was not in their best interests, contrary to the opinion expressed by doctors. The author intends

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5. Re A (Children) (n 3).
to illustrate the point that even in cases such as Re A where the outcome is highly defensible, there are still valid arguments which support the opposite view. It is submitted that the separation in Re A seems far from being a foregone conclusion. Part five will explore situations where doctors are of the view that treatment should be withheld, contrary to parental wishes. Finally the article will address the benefits and risks associated with the views of both doctors and parents and conclude that the courts should modify the ‘best interest’ test to give greater weight to non-medical considerations.

II. THE NATURE OF THE DISPUTE BETWEEN DOCTORS AND PARENTS

Parents who have to make difficult decisions over matters of life and death of their children are placed in a dilemma. The fact that the lives of premature babies and babies with birth defects can now be extended for weeks and months through intensive neonatal care has forced medical teams, parents and the courts to step into a grey area that ‘excites interest and controversy’, and where no easy conclusions can be reached. When God or nature abstains from ending the lives of these children, a decision on whether to continue treatment or not undoubtedly rests on the shoulders of both parents and doctors.

Current medical practice encourages doctors and parents to reach a consensus on the child’s fate and treatment. The Royal College of Paediatrics and Child Health (RCPCH) has offered guidelines that emphasise the importance of a ‘partnership of care’ between doctors and parents that serves the best interests of the child. Resolving differences of opinion between doctors and parents is essential and should be multi-layered. Options such as seeking a second expert opinion, taking legal advice from an independent advocate, holding case conferences, referring the matter to an ethics

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7 Royal College of Paediatrics and Child Health (RCPCH), Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice (2nd edn, RCPCH, May 2004) [2.3.1.1].
8 ibid, [3.4].
committee or utilising mediation services should always be considered in order to salvage a deadlock between clinical and parental opinion. Pursuing the matter before the courts should be a last resort, used only when every possible avenue of reconciling the disagreement has failed.

It is encouraging to see that a majority of disagreements are resolved within the intensive care unit and instances of requiring the courts to adjudicate the matter remain exceptional. Statistics show that 70 per cent of deaths in UK neonatal intensive care units involve discussion between parents and the medical team. In the event that such a dilemma has to be resolved by the courts as a last resort, the question that one would ask is: whose view – the professional or the parental – should be accorded greater weight by the courts?

III. The Development of the Best Interest Test

In Re B (A Minor) (Wardship: Medical Treatment), the Court of Appeal was confronted with a difficult situation where the parents of a child suffering from Down’s syndrome refused to consent to an operation to remove an intestinal blockage that would eventually lead to the child’s death. The court nevertheless overrode the parents’ wishes, contending that withholding treatment was not in the best interest of the child. However, Lord Justice Templeman made an obiter statement that had the effect of shifting away ‘from a commitment to an ethic which affords value to life per se, towards an approach which values certain human characteristics or qualities’. His Lordship held that:

There may be cases... of severe proved damage where the future is so certain and where the life of the child is bound to

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9 General Medical Council (GMC), Treatment and Care Towards the End of Life: Good Practice in Decision Making (GMC, May 2010) [108].
10 RCPCH (n 7) [2.2.1].
12 ibid 1424 (Templeman LJ) 1424 (Dunn LJ).
be full of pain and suffering that the court might be driven to a different conclusion...

Although there is a strong presumption in favour of prolonging the life of the child, this is not absolute if the life can be termed as ‘demonstrably so awful’, ‘intolerable’, or ‘a living death’. It was established in Re J (A Minor) (Wardship: Medical Treatment) that to assess whether it is in the best interest of the child to withhold or to authorise treatment, the courts will undertake a balancing exercise that takes into account ‘the pain and suffering and quality of life which the child will experience if life is prolonged’ and also ‘the pain and suffering involved in the proposed treatment itself’.

Such an approach involves placing the benefits and risks of treatment on a ‘balance sheet’ and to determine on which side the individual case of the child falls. In the words of Justice Holman, the judge is not deciding:

...what decision [he] might make for [himself] if [he] was, hypothetically, in the situation of the patient; nor for a child of [his] own if in that situation; nor whether the respective decisions of the doctors...or the parents...are reasonable decisions.

It is an objective test that depends entirely on the facts of the individual case. Such a ‘balance sheet’ approach was well illustrated in the decision of Re OT. In her judgment, Justice Parker listed 26 factors that pointed to the burdens of continuing treatment and 10 factors to the contrary. In doing so, she concluded that

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14 Re B (n 11) 1424.
16 Re B (n 11) 1424 (Templeman LJ).
17 ibid 1424 (Dunn LJ).
18 Re C (A Baby) [1996] 2 FLR 43 (F) 44 (Sir Stephen Brown).
19 Re J (A Minor) (n 15) 46 (Lord Donaldson).
20 ibid.
21 Re A (Male Sterilisation) [2000] 1 FLR 549 (CA) 560 (Thorpe LJ).
22 An NHS Trust v MB [2006] EWHC 507 (Fam) [16] (Holman J).
23 ibid.
24 [2009] EWHC 633 (Fam).
25 ibid [110]–[135].
26 ibid [136]–[145].
continuing treatment would not be in the best interest of Baby OT. Although it has been stated that ‘best interest encompasses medical, emotional and all other welfare issues’, many commentators have observed that there is a tendency of judicial deference to medical opinion. McLean and Williamson, who termed such a trend as a ‘medicalisation of decisions about life and death’, argued that such deference to medical opinion should be applauded as courts lack the expertise to make clinical judgments.

Pedain has observed that there are cases where courts sided with the parents when they objected to the treatment of the child as opposed to circumstances where doctors refused to continue treatment. One such instance where parental opposition prevailed was Re T (A Minor) (Wardship: Medical Treatment) where the court upheld the parents’ wishes to refuse treatment despite the prospects of the treatment being considerably optimistic. Grubb has hailed the court’s willingness in that decision to look into considerations beyond medical evidence and described such an approach to be ‘refreshing’. Bainham, on the other hand, was more concerned with the erosion of children’s rights when he stated that ‘life or death for these children can therefore be something of a lottery depending not on their best medical interests but on the values and preferences of their parents’. Loughrey, however, adopted a slightly more moderate view on this decision by arguing that in the event of parental opposition, parental views should be taken into account if their opposition would either lead to adverse effects on the welfare of the infant and as a result would warrant the infant’s life to be not worth living, or if the prognosis of a medical treatment

27 Re A (Male Sterilisation) [2000] 1 FLR 549 (CA) 555 (Butler-Sloss P); Re L (Medical Treatment: Benefit) [2004] EWHC 2713 (Fam) [12] (Butler-Sloss P).
28 Morris (n 6) 348; R Heywood, ‘Parents and Medical Professionals: Conflict, Cooperation, and Best Interest’ (2012) 20 Med Law Rev 29, 38; Bolam v Friern Hospital Management Committee [1957] 1 WLR 582 (QB) (McNair J).
29 McLean and Williamson, Impairment & Disability (n 13) 88.
31 [1997] 1 WLR 242 (CA).
remains uncertain.\(^{34}\)

However, it is submitted that the courts’ deference to medical opinion remains prevalent with *Re T*\(^{35}\) as the only exceptional case where the courts have tipped the balance in favour of the parents. In *Re S (A Minor) (Medical Treatment)*,\(^{36}\) *Re O (A Minor) (Medical Treatment)*\(^{37}\) and *Re R (A Minor) (Blood Transfusion)*,\(^{38}\) the courts overrode the parents’ objections to blood transfusion based on their Jehovah’s Witness beliefs. The courts did so on grounds that refusal of a blood transfusion was not in the best interests of the children. These cases were held by Lord Justice Waite in *Re T* to have fallen within the ambit of ‘scruple and dogma’\(^{39}\) and the courts therefore intervened in spite of the parents’ religious beliefs. Hence, it was argued by Fox and McHale that the outcome of *Re T* was specific to its own facts: both parents were health professionals, the mother’s non-cooperation might render the treatment useless, and the fact that they were residing outside of the UK might raise practical difficulties in enforcing the treatment.\(^{40}\)

**IV. Re A – When Parents Withhold Treatment**

The decision of *Re A (Children) (Conjoined Twins: Surgical Separation)*\(^{41}\) has proven controversial in many aspects. The parents of conjoined twins, Jodie and Mary, motivated by religious convictions, opted to leave the fates of the two children to nature. However, the Court of Appeal unanimously ordered the separation to be carried out and, as a result, Mary’s life was taken in order to preserve Jodie’s. This was a difficult case for all three judges in the Court of Appeal. Perhaps their Lordships would have been spared from these difficulties if they had adopted the line of argument proposed by Mason, who points out that Mary should have been considered


\(^{35}\) *Re T* (n 31).

\(^{36}\) [1993] 1 FLR 376 (F) (Thorpe J).

\(^{37}\) [1993] 2 FLR 149 (F) (Johnson J).

\(^{38}\) [1993] 2 FLR 757 (F) (Booth J).

\(^{39}\) *Re T* (n 31) 254.

\(^{40}\) M Fox and J McHale, ‘In Whose Best Interests?’ (1997) 60 MLR 700, 709.

\(^{41}\) *Re A (Children)* (n 3).
a ‘still birth’ since she had never breathed by herself. Accordingly, there was nothing unlawful in carrying out the separation.\textsuperscript{42} Harris reaches a similar conclusion, albeit with different reasoning, in arguing that Mary and Jodie were not ‘persons’ as they did not possess the ‘capacity to value existence’.\textsuperscript{43} They were just like foetuses\textsuperscript{44} or patients in a permanent vegetative state.\textsuperscript{45} Therefore, it was lawful for doctors to undertake the separation,\textsuperscript{46} just as with the withdrawal of life-sustaining treatment in \textit{Airedale NHS Trust v Bland}.\textsuperscript{47}

However, it is respectfully submitted that the distinction drawn by Harris between ‘human being’ and ‘person’ is unsustainable and lacks common sense. If Mary and Jodie, as well as Anthony Bland, were considered to be ‘non-persons’,\textsuperscript{48} then what is the legal position of A if he fails to murder B, who ends up in a permanent vegetative state in hospital? Can we say a later attempt by A to detach the life support machine from B does not amount to murder, because B is a ‘non-person’ which ‘cannot...be deprived by death of something they could coherently be said to value’?\textsuperscript{49}

Even if we agree with Harris’s distinction, and that separation was lawful, one might ask, are we making the right choice in agreeing with the doctors instead of the parents? Why should separation be seen as the ‘lesser of the two evils’\textsuperscript{50} where in fact it is arguable that the lesser of two evils might be letting both Jodie and Mary die? Gillon is of the view that what was morally preferable for the court was to respect the parents’ view of not separating the


\textsuperscript{44} \textit{Vo v France} (2005) 40 EHRR 12: an unborn child did not have a right to life and was not a person within the meaning of Article 2 of the ECHR.

\textsuperscript{45} \textit{Airedale NHS Trust v Bland} [1993] AC 789 (HL): Bland, a victim of the Hillsborough disaster, was in a persistent vegetative state after being treated for two years. The doctors obtained a declaration from the court to stop feeding him by tube.

\textsuperscript{46} Harris (n 43) 232-6.

\textsuperscript{47} \textit{Bland} (n 45).

\textsuperscript{48} Harris (n 43) 234.

\textsuperscript{49} ibid.

\textsuperscript{50} \textit{Re A (Children)} (n 3) 203 (Ward LJ).
twins since they were ‘neither incompetent nor negligent... and their reasoning was not eccentric or merely religious, but was widely acceptable moral reasoning’. It would seem that the court in Re A considered what was in the best interest for the child to be survival, contrary to the result in cases where parental wishes were to save the child. In those cases, the courts have viewed the best interest of the child to include not only survival, but also the prospects of success of the medical treatment and the pain and suffering involved. It is submitted that a best interest test that varies according to the parents’ views is arbitrary as parents will always find themselves on the losing side.

Freeman, however, comments that the court was correct not to subject the rights of the children to parental autonomy. He argues that the notion of parental autonomy rests upon ‘shaky foundations’ and it would be better to take away such a decision from their hands and subject it to ‘principled reasoning’. To him, Jodie had a right to live with dignity whereas Mary had a right to die with dignity; hence the separation was justifiable. Such a viewpoint was also supported by Justice Cazalat when he held that Article 3 of the European Convention on Human Rights confers upon the child a right to die with dignity. Two observations can be made with regard to such an interpretation. Firstly, there are some commentators who disagreed that the Strasbourg jurisprudence confers such a ‘right to die with dignity’. Secondly, the court in Re A initially considered deontological premises, before securing its desired outcome through utilitarianism. This is undesirable,
as the law is left in an inconsistent state where the ethical aspect of individual cases will eventually be decided on the moral perception of different judges.

V. **The Best Interest Test When Doctors Withhold Treatment**

In cases where parents challenge a doctor’s decision of withholding treatment, the judicial approach is more consistent in upholding the latter’s decision. Judges have always refused to follow parental wishes by holding that it is undesirable to insist that doctors treat children in cases that run counter to their medical judgment and conscience.\(^{59}\) This is evident in some cases\(^ {60}\) where judges have adopted the categorisation method introduced by the RCPCH in coming to their decisions. There are five circumstances where withholding or withdrawing treatment is justified: when a child is classed as ‘brain dead’, in a ‘permanent vegetative state’, in a ‘no chance’ situation, in a ‘no purpose’ situation, or in an ‘unbearable’ situation.\(^ {61}\) Although it is less controversial to withhold treatment in the first two circumstances, conclusions might vary and be difficult in the last three situations.\(^ {62}\)

Kennedy has taken the view that professional guidelines may be useful for the purpose of judicial determination so long as judges are mindful that they are the final arbiter over the matter.\(^ {63}\) Unfortunately, members of the RCPCH were critical of those guidelines and some of the choice of words that was used, e.g. ‘no chance’ situation.\(^ {64}\) In 2006, a Working Party for the Nuffield Council of Bioethics issued guidelines on giving intensive care at different
gestational ages. It is submitted that such guidelines are to be welcomed, as it not only takes into account the different level of prognosis of neonates at different gestational ages, but gives greater preference to parental wishes. Only when the child is born before 22 weeks will parents fall out of the picture and no resuscitation will be given unless for research purposes that are approved by a research ethics committee and with informed parental consent.

It is also submitted, however, that some reservations over this approach are needed, as over-deference to medical opinion, especially in cases where parents challenge doctors’ decisions on withholding treatment, may raise questions over the impartiality of judges in these matters. Moreover, the trust and confidence between parents and doctors may be eroded if parents perceive the ‘courts as depriving their child in allowing others’ judgments of best interests to prevail’. This happened in the series of litigation between doctors and parents in Charlotte Wyatt’s case. In the autumn of 2004, the parents reported the doctors to the police for serious offences related to the care provided to their child.

Moreover, Charlotte Wyatt’s parents argued that ventilation should only be withheld if the child’s condition is ‘intolerable’. The courts, however, declined to replace the ‘best interest’ test with the ‘intolerability’ test – the latter being more favourable towards parental autonomy. The court held that:

... the concept of “intolerable to the child” should not be seen as a gloss on, much less a supplementary test to, best interests. It is... a valuable guide in the search for best interests in this kind of case.

By refusing to do so, courts will continue to view children as

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66 ibid [9.16], [9.19].
67 Morris (n 6) 375.
69 Re Wyatt [2004] EWHC 2247 (Fam), [2005] EWHC 117 (Fam), [2005] EWHC 693 (Fam), [2005] EWHC 1181 (Fam), [2005] EWHC 2902 (Fam), [2006] EWHC 319 (Fam).
71 ibid [76] (Wall LJ).
patients rather than sons or daughters. This defeats the spirit of a ‘balancing exercise’ which is supposed to put both medical and parental considerations on the same scale.

VI. ASSOCIATED RISKS IN PARENTAL WISHES AND DOCTORS’ DECISIONS

There are significant risks that courts must bear in mind when undergoing the ‘balancing exercise’. One such risk that may influence doctors’ decisions is the limited resources within the NHS. Studies have revealed that for babies weighing less than one kilogram, the cost per additional survivor is between £85,000 and £174,000 (at 1998 prices). Such a costly operation might prompt doctors to save beds for those who have better chances. It is certainly difficult to rule out such a ‘hidden spectre’ when doctors have come to a decision that saving the infant is futile. Besides, decisions made by doctors may be prompted by other considerations other than the child’s best interest, e.g. their own biases, their feeling of failure etc. As such, there is a strong case against medical opinion having the final say over such decisions.

The same can also be said about parents since most of their decisions are not made ‘in an entirely disinterested manner’. Parents may be ‘sufficiently distressed to lack clarity of thought’, and considerations such as the feasibility of caring for the child in the future might also motivate them to withhold treatment, even if the prognosis is optimistic. The recent case of Neon Roberts, who was seven at the time when his case was widely reported in the media and was then suffering from a malignant brain...

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72 Brazier, ‘An Intractable Dispute: When Parents and Professionals Disagree’ (n 68) 416.
73 Nuffield Council on Bioethics (n 65) [6.34].
74 Brazier, ‘An Intractable Dispute: When Parents and Professionals Disagree’ (n 68) 418.
75 McLean, Old Law, New Medicine (n 2) 122.
76 ibid.
77 ibid 127.
78 ibid.
79 Charlie Cooper, ‘Cancer boy Neon Roberts should have radiotherapy for brain tumour against mother’s wishes, rules judge’ The Independent (London, 21 December 2012) <http://www.independent.co.uk/news/uk/home-
tumour, is illustrative. The boy’s mother went into hiding with her son in order to prevent him from undergoing chemotherapy and radiotherapy treatment. 80 Those treatments have a success rate of around 80 per cent. 81 Justice Bodey in his judgment expressed his worries that the mother’s judgment went ‘awry as to the extent of the seriousness of the threat’ that the boy was facing. 82 His Lordship was also concerned that the mother ‘may have become somewhat overwhelmed by the process’. 83

In short, the position was well summarised by McLean in the following words:

Neither doctors nor parent, then, can necessarily be said to be the best or most appropriate decision makers. Each carries their own prejudices and emotional baggage which may obscure principled assessment of the situation. Nonetheless, each is a key participant in the tragedy which is unfolding. 84

**VII. Conclusion**

Reading through the pages of these decisions is heart-breaking and one cannot help but empathise with the challenges and ethical dilemmas faced by those thrust into these difficult scenarios. But decisions still need to be made even if one of the parties will eventually be disappointed. One must always remember that the courts have encouraged such decisions to be jointly made by both doctors and parents and it is only in the most extreme circumstances that the courts are forced to make a choice. However, one should not be optimistic that all differences can be resolved without the court’s intervention. There is still a pressing need for the courts to redefine the scope of the best interest test to accommodate more non-medical factors, e.g. the psychological well-being and future

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81 An NHS Trust v SR [2012] EWHC 3842 (Fam) [1] (Bodey J): the judge ruled against the mother’s objection to chemotherapy and radiotherapy treatment.
82 ibid [21].
83 ibid [22].
84 McLean, *Old Law, New Medicine* (n 2) 127.
development of the infant. A ‘balancing exercise’ cannot be well achieved if medical factors are given more weight than non-medical ones. More importantly, the ‘balancing exercise’ should be made with a view to preserving the trust and confidence between doctors and parents or guardians.

Given that there are associated risks in preferring one view over the other, it is submitted that no one is or should be in a better position to decide upon the issue. A redefined best interest test as advocated above is useful for the resolution of these conflicts. However, it is argued that there may be instances where the best interest test is unable to offer a solution that accommodates both parental wishes and medical opinion. The practical solution will always be to take all possible measures to prevent divergence in opinion between the loving parents and the responsible doctors in making decisions of life and death.