Neutral Citation Number: [2021] EWCA Civ 1018

Case No: B4/2021/1044

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE HIGH COURT OF JUSTICE
FAMILY DIVISION
The Hon Mr Justice MacDonald
MA20P02742

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 9 July 2021

Before :

LORD JUSTICE BAKER
LADY JUSTICE CARR
and
LADY JUSTICE ELISABETH LAING

- -

IN THE MATTER OF THE SENIOR COURTS ACT 1981
AND IN THE MATTER OF THE CHILDREN ACT 1989
AND IN THE MATTER OF ALTA FIXSLER

Between :

MRS FIXSLER (1) **MR FIXSLER (2)**	**Appellants**
- and -	
MANCHESTER UNIVERSITY NHS FOUNDATION TRUST (1) **ALTA FIXSLER (2)** **(by her children's guardian)**	**Respondents**

- -
- -

Stephen Simblet QC and Stephen Lue (instructed by **Harris da Silva**) for the **Appellants**
Helen Mulholland (instructed by **Weightmans LLP**) for the **First Respondent**
Fiona Holloran (instructed by **McAlister Family Law**) for the **Second Respondent**

Hearing date : 23 June 2021

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Approved Judgment

Covid-19 Protocol: This judgment was handed down remotely by circulation to the parties' representatives by email, release to BAILII and publication on the Courts and Tribunals Judiciary website. The date and time for hand down is deemed to be 2pm on 9 July 2021.

LORD JUSTICE BAKER :

1. These proceedings are about a little girl, Alta, now aged two and a half, who suffered catastrophic brain injuries at birth. Tragically, she is unlikely to live for longer than the next two years or so. The clinicians treating her have concluded that it would be in her best interests for the life-sustaining treatment on which she depends to be withdrawn. The unanimous view of the medical experts who have given evidence hitherto is that she is suffering consistent pain. Her parents disagree. They do not want the treatment to be withdrawn. They do not accept that she is in consistent pain. Furthermore, they are devout Hasidic Jews for whom the sanctity of life is a fundamental tenet. They propose that Alta be transported to Israel where her treatment can continue in hospital and where, when she dies, as they accept she will in her childhood years, she can be buried in accordance with their religious beliefs and practices. The treating clinicians here in England say that the journey to Israel would cause her to suffer further pain for no medical benefit and is not in her best interests.

2. The NHS Trust responsible for the hospital where Alta is being treated applied to the Family Division for orders authorising the withdrawal of life-sustaining treatment. On 28 May 2021, MacDonald J made a declaration that it was not in her best interests for such treatment, including mechanical ventilation, to be continued and that she should be moved to a palliative care pathway, and ordered that the doctors be at liberty to treat her in accordance with their clinical discretion. The parents wish to appeal against that decision.

Background

3. Alta's parents are Hasidic Jews and Israeli citizens. They moved to the UK in 2014. They have an older child now aged 8. Alta was born on 23 December 2018, eight weeks premature. During her birth, she suffered a severe hypoxic ischaemic brain injury. It is accepted that this will inevitably result in early death. Estimates of her future life expectancy range from six months to two years.

4. Alta is an inpatient at a hospital run by the Manchester University NHS Foundation Trust. The details of her medical history and treatment are set out in MacDonald J's judgment. In summary, much of her brain structure has been lost. She has extensive multicystic encephalomalacia, although elements of her cerebral cortex remain, together with a limited amount of her thalami and a small area of her cerebellum. There is also damage to her brain stem. At paragraph 9 of his judgment, the judge summarised her current symptoms as follows:

> "i) An inability to maintain an open airway and adequate ventilation to sustain life for any significant period of time without support.
>
> ii) An inability to protect her airway.
>
> iii) An inability to maintain core body temperature.
>
> iv) An inability to blink and protect the corneal surface of the eyes, optic atrophy, an inability to perceive light and darkness and repeated ulceration of the corneas.

> v) An inability to perceive sound due to injury to the auditory cortex.
>
> vi) Sustained severe spasticity (stiffness from constant contraction of muscles) of the whole body which will increasingly lead to more permanent joint contractures (joints stuck in same position as they are always stiffly held that way by the damaged brain) and scoliosis (a bent spine).
>
> vii) Spinal clonus (contracting jerks of the body triggered by the spine that is not modulated by a brain).
>
> viii) Severe spasticity (requiring medication, positioning for comfort and prevention of contractures, which have already developed in some of the joints of her hands).
>
> ix) An inability to swallow.
>
> x) Seizures.
>
> xi) Global development delay."

As a result, she is mechanically ventilated via a tracheostomy and fed via a tube.

5. There is a medical consensus that Alta has no conscious awareness, although her parents contend that she responds to their touch. A central feature of the case before the judge was whether she was able to experience pain.

6. Alta has been an inpatient in the hospital's paediatric intensive care unit since birth. After prolonged discussions about treatment options, the clinicians concluded that life-sustaining treatment should be withdrawn. The parents disagreed and requested a second opinion. As a result, the Trust obtained independent reports from Dr Martin Samuels, a consultant respiratory paediatrician at Great Ormond Street Hospital, and Dr Anthony Hart, a consultant paediatric neurologist at Sheffield Teaching Hospital. Both doctors considered the medical records and examined the child, and Dr Hart also met the parents. Each doctor prepared a report agreeing with the clinicians' diagnosis and with the proposal to withdraw life-sustaining treatment and transfer Alta to palliative care. In September 2020, a meeting took place between the clinicians and the parents at which the second opinions were discussed. The parents continued to oppose the hospital's plan.

7. On 18 December 2020, the Trust applied to the High Court seeking (1) a declaration under its inherent jurisdiction that it was not in Alta's best interests for the treatment to be continued and that it was in her best interests for a palliative care regime to be implemented, and (2) leave to apply for a specific issue order under s.8 of the Children Act determining that such treatment should cease to be provided and a palliative care regime implemented. In support of the application, the trust filed statements from Dr A and Dr B, Alta's treating clinicians, which included a number of attachments, including the reports from Dr Hart and Dr Samuels.

8. At a case management hearing on 29 January 2021, a children's guardian was appointed to represent Alta, and she was given permission to instruct a medical expert "in a

relevant discipline" to advise on Alta's diagnosis, prognosis and best interests. The parents were given permission to obtain a report from a paediatric respiratory consultant as to whether Alta was suitable for long term ventilation at home and on the practicalities of international travel to an Israeli hospital. The parents' representatives did not seek a report from a neurologist but were given permission to put questions to Dr Hart, Dr Samuels, and to the hospital paediatric intensivist, Dr B. Questions were duly put by the solicitors acting for the parents and for the guardian to the three doctors, each of whom responded in a further report, or, in Dr B's case, a second statement in the proceedings. The parents' solicitor filed statements from the father and from Rabbi Yisroel Goldberg, who had supported the parents since Alta's birth, provided religious advice and guidance, and had accompanied them to many meetings with the Trust. The parents' solicitor also obtained and filed a report from Dr Rob Ross Russell, a consultant paediatrician at Addenbrooke's Hospital in Cambridge. (Technically this instruction was outside the permission granted by the judge, but no party raised any objection.) He also concluded that it was not in Alta's best interests to continue with life-sustaining intervention. In the event, the guardian elected not to obtain a further expert opinion but she filed an extensive report supporting the Trust's application.

9. The hearing took place before MacDonald J on 19 to 21 May 2021. The judge heard oral evidence from Dr Samuels, Dr Hart, Dr Ross Russell, Dr A, Dr B, Alta's parents, Rabbi Goldberg, and the guardian. Judgment was reserved and handed down on 28 May when the order was made authorising the withdrawal of treatment.

10. On 15 June, the parents, having changed their legal representatives, filed a notice of appeal seeking permission to appeal against the order. On the same day, I directed that the application for permission to appeal be listed for an oral hearing before a full court on 23 June 2021, with appeal to follow if permission was granted, and stayed the order pending determination of the application and, if granted, the appeal. On 18 June, the parents' representatives filed an application to adduce fresh evidence, which I directed should be considered at the start of the hearing of the application.

The Law

11. As McFarlane LJ observed in *Yates v Great Ormond Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, [2018] 4 WLR 5 at para 112:

> "As the authorities to which I have already made reference underline time and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

This Court having very recently traversed this ground in *Re Pippa Knight* [2021] EWCA Civ 362, it might be thought unnecessary to consider the legal principles again in any detail. But the challenge to the judge's interpretation of the law in this case has focused on a different argument. Further discussion of the principles is therefore unavoidable, even if it involves an element of repetition.

12. There are two principal tests which have been devised by lawyers and ethicists for making decisions for persons who lack capacity. One is the best interests test, under which (in its simplest form) a decision-maker decides what is best for the person

concerned. The second is the so-called "substituted judgment" test, by which the decision-maker tries to put himself in the position of the person lacking capacity and make the decision in the way he or she would have decided. Under the law of England and Wales, the test to be applied in cases about medical treatment of both children and mentally incapacitated adults is called the best interests test but in each case contains an element of substituted judgment. One of the principal issues arising in this case is the importance to be attached to that element when making the decision whether to authorise the withdrawal of Alta's life-sustaining treatment.

13. The proposition that the best interests test contains an element of substituted judgment can be illustrated by reference to the case law.

14. The jurisdiction to make orders authorising the withdrawal of treatment from a child, and the centrality of the best interests principle within that jurisdiction, were established in a series of cases in the latter decades of the last century, culminating in *Re J (A Minor) (Wardship: Medical Treatment*, [1991] Fam 33. At p 44 D to E, Lord Donaldson of Lymington said, when summarising how a decision whether or not to continue treatment was taken:

> "The choice is that of the patient, if of full age and capacity; the choice is that of the parents or court if, by reason of his age, the child cannot make the choice and it is a choice which must be made solely on behalf of the child and in what the court or parents conscientiously believe to be his best interests."

At p46 D to F he stated:

> "there is a balancing exercise to be performed in assessing the course to be adopted in the best interests of the child …. This brings me face to face with the problem of formulating the critical equation. In truth it cannot be done with mathematical or any precision. There is without doubt a very strong presumption in favour of a course of action which will prolong life, but … it is not irrebuttable ….[A]ccount has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment itself."

15. At 46 H to 47 B he continued with this observation which contains an element of substituted judgment:

> "We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life. As explained, this formulation takes account of this and also underlines the need to avoid looking at the problem from the point of view of the decider, but instead **requires him to look at it from the assumed point of view of the patient**. This gives effect, as it should, to the fact that even very severely handicapped people find a quality of life

> rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's, desire to survive [emphasis added]."

16. The approach to be followed by a court faced with an application to withdraw treatment was succinctly summarised by this Court in *Wyatt v Portsmouth Hospital NHS Trust* [2005] EWCA Civ 1181 where the judges, having considered various earlier authorities including *Re J (A Minor) (Wardship: Medical Treatment*, supra, and *Re A (Male Sterilisation)* [2000] 1 FLR 549, observed (at paragraph 87):

> "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 patient (*Re J*)**. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (*Re J*). The term 'best interests' encompasses medical, emotional, and all other welfare issues (*Re A*). The court must conduct a balancing exercise in which all the relevant factors are weighed (*Re J*) ….[emphasis added]"

17. These passages demonstrate that the test is best interests but it includes an element of substituted judgment in the form of a requirement to look at the question from the patient's assumed point of view. It is important to emphasise, however, that the element of substituted judgment is no more than that. The fundamental test remains the best interests of the child and the responsibility for carrying out that evaluation lies with the judge.

18. The courts have applied a similar approach when exercising the jurisdiction relating to mentally incapacitated adults. In what is now the leading authority, *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591, a case concerning an adult patient receiving clinically-assisted nutrition and hydration, Baroness Hale of Richmond said (at paragraph 39):

> "The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his

> welfare, in particular for their view of what his attitude would be."

At paragraph 45, she set out the approach to the patient's wishes, feelings, beliefs and values:

> "In so far as Sir Alan Ward and Arden LJ [in the Court of Appeal] were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being."

19. The courts have therefore adopted a similar approach whether the subject of the application is an adult or a child. In her analysis of the legal principles in *Aintree*, Baroness Hale cited a number of cases involving children, including *Re J (A Minor) (Wardship: Medical Treatment* and *Wyatt v Portsmouth Hospital NHS Trust*. And passages from her judgment in the *Aintree* case have been cited by in cases involving the withdrawal of treatment from children, including in judgments of this Court in *Re A (A Child)* [2016] EWCA Civ 759 and *Re Pippa Knight*. But as my Lady Elisabeth Laing LJ pointed out in the course of submissions in the present case, the statutory provisions applicable in children's cases are not the same as those governing cases involving mentally incapacitated adults. Does this make any difference to the approach to be followed by the court?

20. Cases involving a mentally incapacitated adult ("P"), such as the *Aintree* case, will now normally be brought under the Mental Capacity Act 2005 rather than under the inherent jurisdiction. That Act includes, in s.4, statutory obligations to be followed by a person (including a court) determining what is P's best interests. Under s.4(6) such a person must

> "consider, so far as is reasonably ascertainable—
>
> (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

> (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
>
> (c) the other factors that he would be likely to consider if he were able to do so."

Under s.4(7), the decision-maker "must take into account, if it is practicable and appropriate to consult them," the views of persons falling into categories listed in the subsection, including "anyone engaged in caring for the person or interested in his welfare" as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6). In the case of a mentally incapacitated adult, therefore, the requirement to consider the question from the assumed point of view of the patient is now a statutory obligation.

21. In the *Aintree* case, Baroness Hale, having recited the provisions of s.4, observed (at paragraph 23):

> "This approach follows very closely the recommendations of the Law Commission in their *Report on Mental Incapacity* (1995, Law Com No 231) on which the 2005 Act is based. It had been suggested in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 that it might be enough if the doctor had acted in accordance with an accepted body of medical opinion (the *Bolam* test for medical negligence). However, as the Court of Appeal later recognised in *Re S (Adult Patient: Sterilisation)* [2001] Fam 15, there can only logically be one best option. The advantage of a best interests test was that it focused upon the patient as an individual, rather than the conduct of the doctor, and took all the circumstances, both medical and non-medical, into account (paras 3.26, 3.27). But the best interests test should also contain "a strong element of 'substituted judgment'" (para 3.25), taking into account both the past and present wishes and feelings of patient as an individual, and also the factors which he would consider if able to do so (para 3.28). This might include "altruistic sentiments and concern for others" (para 3.31). The Act has helpfully added a reference to the beliefs and values which would be likely to influence his decision if he had capacity. Both provide for consultation with carers and others interested in the patient's welfare as to what would be in his best interests and in particular what his own views would have been. This is, as the Explanatory Notes to the Bill made clear, still a "best interests" rather than a "substituted judgment" test, but one which accepts that the preferences of the person concerned are an important component in deciding where his best interests lie. To take a simple example, it cannot be in the best interests to give the patient food which he does not like when other equally nutritious food is available."

22. What are the statutory obligations in cases involving children? Under s.1 of the Children Act 1989, when a court determines any question with respect to the upbringing of a child, the child's welfare is the paramount consideration. Applications under the

inherent jurisdiction for a declaration authorising medical treatment are determined according to the child's best interests. But welfare and best interests are one and the same thing. As I observed in *Re Pippa Knight* at paragraph 69:

> "I can find no basis for distinguishing between the two concepts. On the contrary, the case law demonstrates that the terms are normally used interchangeably."

23. In the present case, the Trust's application was not only for a declaration under the inherent jurisdiction but also for a specific issue order under s.8 of the Children Act 1989. A court determining an application for an order under s.8 is required to have regard to the factors in s.1(3), the so-called welfare checklist:

> "(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 under this Act in the proceedings in question."

24. Although the checklist includes "the ascertainable wishes and feelings of the child concerned (considered in the light of his age and understanding)", it does not expressly include provisions equivalent to those in s.4(6) of the Mental Capacity Act which require a decision-maker to consider, so far as reasonably ascertainable, "the beliefs and values that would be likely to influence his decision if he had capacity" or "the other factors that he would be likely to consider if he were able to do so" .

25. This distinction was considered by MacDonald J in another recent case, *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2530 (Fam), [2020] 3 All ER 663, which concerned a child whose circumstances were in some respects similar to Alta's. Tafida Raqeeb was a 5-year-old girl who was being kept alive by artificial ventilation in hospital after sustaining irreversible brain damage shortly before her fifth birthday from which there was no prospect of recovery. The hospital Trust applied for a declaration authorising the withdrawal of treatment and that application was also listed before and decided by MacDonald J. Tafida also came from a devoutly religious family – in her case, a Muslim family. Her parents' religious beliefs precluded them from consenting to the withdrawal of life-sustaining treatment, and, like Alta's parents, they proposed that she be transferred for treatment in another country, in her case to a hospital in Italy

where doctors had offered to carry out an operation which would have allowed her to be cared for at home. In contrast to the present case, however, the preponderance of the medical evidence indicated that that Tafida was unlikely to experience pain. Furthermore, in contrast to the medical prognosis for Alta, which is that her life expectancy is between six and twenty-four months, the opinion in Tafida's case was that, if kept on mechanical ventilation, she would live for a further ten to twenty years. Finally, as he explained in the last sentence of practice 168 of his judgment, Tafida had a "formative appreciation that life is precious, a wish to follow her parents' religious practice and a non-judgmental attitude to disability", for the reasons which MacDonald J gave in paragraphs 166-168 of his judgment, which I quote in paragraph 30, below.

26. All cases in this area are essentially fact-specific and it is unnecessary to consider the best interests analysis in *Raqeeb* in any detail. What is relevant, however, is the judge's approach to looking at the question from the child's "assumed point of view". Counsel in *Raqeeb* submitted that, following the *Aintree* case, "substituted judgment" informed by the beliefs and values of the patient, as identified by others who know the patient, was now "the key driver of the court's best interests decision" and that the consequence of the decision in the *Aintree* case was that, in cases concerning children, whilst not determinative or a legally magnetic factor, the child's beliefs and values must be given something like pre-eminent weight.

27. MacDonald J rejected this submission at paragraphs 122-4:

> "122. It is clear that the starting point of the court's analysis is to consider the matter from the assumed point of view of the child. The court must ask itself what the child's attitude to treatment is or would be likely to be. Within this context, in accordance with s.1(3)(a) of the Children Act 1989, the ascertainable wishes and feelings of the child on this question, which will include his or her values and beliefs, must be considered and be given appropriate weight in light of the child's age and understanding. But that is a very different to the proposition that the child's values and beliefs must start with elevated importance or some pre-assigned weight in the balance. Whilst I accept that paragraphs [22] and [39] of judgment of Baroness Hale in *Aintree* are often cited in cases concerning children as conveniently encapsulating the overall approach to best interests in medical cases (and were used in this way by Hayden J in *Manchester CC v M* [2019] EWHC 468 (Fam)), I do not read those passages as *requiring* the court to give preferential weight to the values and beliefs of the child in the balancing exercise …. [T]he position under s 1(3)(a) of the Children Act 1989 is clear. The wishes and feelings of the child do not carry any presumption of precedence over any of other the other factors in the welfare checklist. The child's wishes and feelings are only one factor in the case and the court is not bound to follow it. Having regard to the words of section 1(3)(a), what governs the weight to be attached to any ascertainable values or beliefs of the child in each case is the principle of the evolving capacity of the child, expressed as a function their age and

understanding. The weight to be attached to the child's wishes and feelings will depend on the particular circumstances of each case and the final decision is that of the court and not of the child (see *Re P (Minors)(Wardship: Care and Control)* [1992] 2 FCR 681). At all times, the child's best interests are the court's paramount consideration and this demands that other factors, including the wishes and feelings of the child, may, in a given case, outweigh the ascertained beliefs and values of the child. Thus, whilst in an individual case, the child's values and beliefs may attract the most weight, in all cases they start with an equal value to that of all other relevant factors.

123. …[I]n cases under the Children Act 1989, and in particular those cases concerning the medical treatment of younger children and infants, it is not helpful to seek to import, wholesale, principles from the Mental Capacity Act 2005. To take Mr Sachdeva's submission regarding values and beliefs as an example, beyond the obvious fact that children below the age of 16 are outwith the jurisdiction of the 2005 Act, that Act deals with a fundamentally different constituency of people to that of the Children Act 1989. Within this context, the emphasis placed on beliefs and values by s 4(6) … is consistent with the fact that those with whom the Mental Capacity Act 2005 is concerned, namely adults and children over the age of 16, are more likely to have developed sophisticated religious, moral or philosophical beliefs and values before losing capacity and to have discussed them with others than are the young children or infants that the Children Act 1989 is often concerned with. Given the fact of evolving capacity, the sophistication of the values and beliefs of those children vary widely in accordance with their age and understanding, the concepts of thought, conscience and religion implying a developing capacity to understand, appreciate and engage rationally with competing ideas and beliefs and, ultimately, the fully formed capacity to exercise choice in respect of those ideas and beliefs. These matters explain the wider wording of s 1(3)(a) of the Children Act 1989 and why it is well suited to evaluating the proper weight to be attached to the widely differing sophistication of children's values and beliefs (see *Re P (Section 91(14) Guidelines)(Residence and Religious Heritage)* [1999] 2 FLR 573) and highlight the undesirability of placing a gloss on s 1(3)(a) by using s 4(6) of the 2005 Act.

124. To use ss 4(6) and 4(7) of the Mental Capacity Act 2005 to add a gloss to s 1(3)(a) of the 1989 Act risks imputing to a young child matters beyond their comprehension and failing to take account of [the] principle of evolving capacity (which is nowhere mentioned in s 4(6) of the 2005 Act), contrary to the express requirement by s 1(3)(a) of the 1989 Act. This is a particular risk where one is dealing with the complex area of religious belief, where the child's age and understanding is key

> to determining the weight to be attached to any such belief. Within this context, I again note the terms of Art 6(2) of Council of Europe's Convention on Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, which stipulates that 'The opinion of the minor shall be taken into consideration as an increasingly determining factor in proportion to his or her age and degree of maturity.'"

28. I agree with MacDonald J's analysis of the law in those paragraphs from his judgment in ***Raqeeb***. Whilst in an individual case, the child's values and beliefs may attract the most weight, in all cases they start with an equal value to that of all other relevant factors. To use ss.4(6) and 4(7) of the Mental Capacity Act 2005 to add a gloss to s.1(3)(a) of the 1989 Act risks imputing to a young child matters beyond their comprehension. I add one further observation. The fact that the welfare checklist in s.1(3) does not expressly refer to a child's values and beliefs does not mean that her culture and religion plays no part in the welfare assessment of a young child. On the contrary, s.1(3)(d) requires the court to have regard to the child's "background and any characteristics of his which the court considers relevant". In doing so, the court must in an appropriate case take into account the religion and culture into which the child is born, and the likelihood of the child following the practices and tenets of the religion. Those factors are part of the child's background and characteristics.

29. I see no inconsistency between the provisions of the welfare checklist in s.1(3) and the proposition clearly established in the case law that a judge considering an application concerning a child's medical treatment has to look at the question from the assumed point of view of the patient. But neither the ascertainable wishes and feelings of the child nor the child's background and characteristics carry any presumption of precedence over any of other the other factors in the welfare checklist. The weight to be attached to the child's wishes and feelings, and to her background and characteristics, will depend on the particular circumstances of each case.

30. Further on in his judgment in ***Raqeeb***, MacDonald J applied this approach to the facts of the case before him:

> "166. Taking as a starting point the assumed view of Tafida, there are obvious difficulties in a judge seeking to place him or herself in the shoes of a four year old child. However, the court must do the best it can on the evidence available. In this case, the parents and the maternal aunt in particular urge upon the court evidence of Tafida's understanding of the religious tradition in which she was being raised as the basis for establishing Tafida's assumed view on the question of whether or not treatment should continue. Within this context, I accept the submission of Ms Gollop and Mr Gration that caution is needed when seeking to establish an assumed point of view for Tafida as a basis for taking account of her wishes and feelings. In relation to matters of thought, conscience and religion, children will move along a continuum from relying on the direction and guidance provided by their parents to ultimately having their own ideas and making their own choices about matters of religion and conscience. In the formative stages, their understanding will not be

sophisticated. On the evidence available to the court, I am satisfied that that is the position in this case. It is plain on that evidence that Tafida had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability. However, and as fairly conceded by the mother, given Tafida's age and understanding, I am also satisfied that she would have had in February 2019 no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises.

167. Within this context, in seeking an assumed point of view for Tafida as a starting point, it is important that the subject matter of that assumed view is properly formulated by reference to the issue before the court. In the context of this case, that subject matter is framed by the Trust as a bare situation of continued life likely, but not certainly, pain free but in a situation of minimal or no awareness, with no hope of recovery and the certain prospect of developing further debilitating conditions, which with any improvement in awareness will further burden Tafida. On the evidence, this is an accurate but as I will come to, incomplete formulation. Within this context, a formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability is very different to the far more complex concept of living a life of minimal awareness with no prospect of substantive recovery. In such circumstances, and notwithstanding her developing conception of the value of life and of the religion in which she was being raised, I accept that it would be unsafe to infer from the available evidence an acceptance by Tafida of, or wish to live, such an existence *per se.*

168. However, in this case I am satisfied that the subject matter of Tafida's assumed view must be framed somewhat more widely than the formulation contended for by the Trust having regard to the medical consensus between the doctors in this jurisdiction and in Italy of what can ultimately be achieved for Tafida, namely care by her family at home on ventilation in the same manner as children in a similar position to Tafida elsewhere in this jurisdiction. Further, I must also bear in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that a child's attitude is often influenced by the views, beliefs and guidance of his or her parents. Within this context, whilst for the reasons I have set out above I am cautious about imputing to Tafida any sophisticated views generally given her age the levels of religious, I am satisfied that if Tafida was asked she would not reject out of hand a situation in which she continued to live, albeit in a moribund and at best minimally conscious state, without pain and in the loving care of her dedicated family,

> consistent with her formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability."

31. In *Raqeeb*, MacDonald J refused the Trust's application. His reasons for doing so were summarised at paragraph 186:

> "The court must face head on the question of whether it can be said that the continuation of life sustaining treatment is in Tafida's best interests. There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive. In this context, I do not discount the grave matters prayed in aid by the Trust. However, the law that I must apply is clear and requires that the best interests decision be arrived at by a careful and balanced evaluation of *all* of the factors that I have discussed in the foregoing paragraphs. Having undertaken that balance, in circumstances where, whilst minimally aware, moribund and totally reliant on others, Tafida is not in pain and medically stable; where the burden of the treatment required to keep her in a minimally conscious state is low; where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to placing her in a position where she can be cared for at home on ventilation by a loving and dedicated family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction; where there is a fully detailed and funded care plan to this end; where Tafida can be safely transported to Italy with little or no impact on her welfare; where in this context the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised; where, in the foregoing context, transfer for treatment to Italy is the choice of her parents in the exercise of their parental responsibility and having regard to the sanctity of Tafida's life being of the highest importance, I am satisfied, on a fine balance, that it is in Tafida's best interests for life sustaining treatment to continue…."

32. In the present case, however, MacDonald J reached the opposite conclusion. His reasons for doing so are set out in his judgment, to which I now turn.

The judgment in this case

33. At the start of his judgment, MacDonald J summarised the background and Alta's medical condition. At paragraphs 13 to 37, he considered at length the evidence (a) as to whether she was exhibiting movements which, if she is able to experience pain, would cause her pain, and (b) whether she was in fact experiencing pain. He then considered the future options for treatment and care (paragraphs 38 to 43), noting that it was the unanimous view of the treating clinicians and experts, including Dr Ross Russell who had been instructed on behalf of the parents, that it was in her best interests

now to withdraw life-sustaining treatment and move her to a palliative care regime. At paragraphs 44 to 45, he set out the evidence as to her prognosis and life expectancy, and noted the medical evidence, in particular from Dr Hart, about the likelihood that her condition will worsen the longer she stays alive. At paragraphs 46 to 48, he summarised the views of the medical experts and clinicians as to her best interests, and the opinion of the guardian. There was unanimity amongst all those witnesses that the Trust's application should be granted.

34. The judge then set out in detail the parents' case at paragraphs 49 to 55 of his judgment. He recorded that it was their primary case that she should be transferred to Israel for continuing life sustaining treatment. He observed, however, that the details of this proposal were "unhelpfully sparse". He set out in some detail the evidence presented to him about the tenets of their Hasidic faith, drawing on the helpful evidence given by Rabbi Goldberg. He cited in particular the central value of the sanctity of life, and the fact that it was strictly forbidden to actively shorten a life, a proscription which extended to the withdrawal of life-sustaining treatment.

35. The judge then summarised the well-established legal principles, citing a number of cases, including *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, his own decision in *Raqeeb v Barts NHS Foundation Trust and others* [2019] EWHC 2530 (Fam), and the recent decision of Poole J in *Guy's and St Thomas Children's NHS Foundation Trust v Pippa Knight* [2021] EWHC 25 (Fam), upheld on appeal by this Court in *Re Pippa Knight* [2021] EWCA Civ 362. He did not, however, refer expressly to s.1(3) of the Children Act. On this occasion, counsel then acting for the parents did not draw an analogy with s.4(6) of the Mental Capacity Act, although they appended paragraphs 115 to 139 of the judgment in *Raqeeb* to their skeleton argument.

36. Having considered the legal principles, the judge said:

> "71. In these circumstances, I have no hesitation in accepting the submission that an assessment of the various dimensions of Alta's best interests must take into account the particular religious, cultural and ethical context of this case provided by the fact that Alta is an Israeli citizen, the fact that the family intended to emigrate with Alta to Israel and the family's Orthodox Jewish beliefs and that the assessment of her best interests must be informed by consideration of the religious and cultural values of the family, and by recognition that religious and ethical frameworks governing these subjective factors differ….
>
> 72. However, within the well-established legal framework summarised above, such matters remain at all times simply factors to be placed into the *overall* best interests evaluation, which factors may or may not drive the outcome of that evaluation depending on the nature and strength of all of the other factors, both medical and non-medical, that fall properly to be placed in the best interest analysis on the particular facts of

> the case. Within this context, I reject the submission of Ms Butler-Cole and Dr George that "the best interests decision-making process can and must be framed within the Jewish belief system in this case." Rather, the Jewish belief system followed by the parents is *one* factor to be weighed in the balance by the court when reaching a best interests decision. For reasons I will come to, I am likewise not able to accept the submission that the assessment of Alta's perspective should start from the assumption that Alta would share the values of her parents, of her brother, and of her wider family and community."

37. In drawing the strands of the evidence together, the judge found (paragraph 78) that

> "there is no dispute that Alta has sustained a catastrophic brain injury from which she will not recover and in respect of which there is no treatment that will improve her current condition. There is likewise no dispute that this injury will severely limit Alta's life expectancy."

On the basis of the medical evidence, the judge concluded that Alta

> "does consistently exhibit movements that, if she is able to experience pain, will cause her pain, in the form of regular spasms in response to handling during care tasks and in response to medical interventions"

and that

> "the balance of the clinical and expert medical evidence before the court is that, over an extended period of time, Alta consistently exhibits whole body spasms in response to handling, care giving and treatment."

In reaching this conclusion, he preferred the medical evidence to that of the parents and Rabbi Goldberg, for several reasons (paragraph 82):

> "First, it is not disputed by the parents or Rabbi Goldberg that Alta does sometimes exhibit spasms when handled and when subjected to treatment. Second, ... the parents have had little contact with Alta in hospital. This must necessarily reduce significantly the weight the court can attach to the parents' assertions regarding the nature and pattern of Alta's response to handling, care and treatment. Whilst Rabbi Goldberg visits more often, his interaction with Alta is less comprehensive than that of the treating clinicians and nursing staff. Third, the parents are, inevitably, in these very difficult circumstances subject to the flattering voice of hope…. Fourth, neither the parents nor Rabbi Goldberg are medically qualified and necessarily observe Alta's responses from a lay perspective rather than a medical one."

The judge also preferred the evidence of the treating clinicians and Dr Samuels and Dr Hart to that of Dr Ross Russell, who had spent far less time with the child, but who in any event, as the judge noted, had concluded that it was "indisputable" that Alta does have episodes of spasm on handling, care giving and treatment.

38. Having concluded that Alta does exhibit whole body spasms, the judge proceeded to find that as a result she would suffer pain. He accepted that this was a more difficult question to answer, but was satisfied on the evidence, including the evidence of Dr Samuels and Dr Hart, and of the treating clinicians, in particular Dr A, who had prepared the pain report, that on a balance of probabilities, she does experience pain. At paragraph 87, he said:

> "I accept the evidence of Dr Hart and Dr A that the anatomical pathways that mediate the reflexive response pain are, to a greater or lesser extent, intact in Alta. Dr A's detailed evidence in this regard demonstrates to my satisfaction that although both Alta's brain stem and her thalami are damaged they are still partially functional and that therefore critical structures for perception of pain remain present and therefore she can still perceive pain."

At paragraph 88, he added:

> "I am further satisfied that the evidence before the court demonstrates on the balance of probabilities that Alta remains able generate a reflex to pain, albeit that she lacks the cerebral structures to derive meaning from this or any understanding of the pain."

His conclusion was based in part on Dr Hart's assessment that Alta experiences consistent, rather than constant, pain. In reaching this conclusion, he held that he was unable to attach significant weight to the opinion of Dr Ross Russell whose examination of the child had been relatively limited and who had conceded that as a paediatrician he was not an expert on pain and had deferred to the paediatric neurologists.

39. It was the judge's assessment (paragraph 90) that her experience of pain represents a significant burden to Alta, although he conceded (paragraph 91) that

> "we have no means of knowing the exact *nature* of her experience of pain given the catastrophic nature of her brain damage."

Despite this, he concluded (paragraph 92) that

> "there is no reason to consider that such pain would be experienced by Alta any other way than as a negative experience. Indeed, the experience of pain without the ability to understand it is arguably an even worse predicament than pain accompanied by understanding."

40. The expert evidence did not enable him to arrive at a definitive assessment of Alta's life expectancy. On the upper estimates before the court,

> "it is possible that Alta may, subject to the continuation of intensive care and in all likelihood an escalation in that level of care, remain alive for two or more years" (paragraph 93).

Importantly however, he added (paragraph 94):

> "On the evidence before the court, I am further satisfied that over the remainder of her short life it is more probable than not that Alta's condition will significantly deteriorate …. I accept the expert evidence of Dr Hart that Alta's symptoms are going to worsen, and she will accumulate further comorbidities that will increase the burden of pain that I am satisfied that she is bearing, including worsening dystonia and spasticity with associated pain, hip dislocation and pain, scoliosis, which may be painful, pressure sores, corneal abrasions and ulcers, and urinary tract infections"

41. The judge then turned to his best interests analysis. In doing so, he followed the approach prescribed by case law:

> "95. The starting point in the analysis of Alta's best interests is to consider the matter from the assumed point of view of Alta. As I have noted elsewhere, there are inherent and obvious difficulties in a judge seeking to place him or herself in the shoes of a two year old child. In undertaking this difficult exercise I am not able, in circumstances where Alta suffered a brain injury that left her with no ability to learn about the world around her before she was able to understand anything of religion and culture into which she was born, to accept the submission that the assessment of Alta's perspective on this matter should start by assuming, without more, that Alta would share the values of her parents, of her brother, and of her wider family and community. I accept that a child's attitude may be, and indeed often is influenced by the views, beliefs and guidance of his or her parents. But the child remains an individual in his or her own right. In some cases, of which *Raqeeb* was an example, there may be evidence that will allow the court to make an informed judgment as to the extent to which a child shares in their parents' values and the values of their community and factor that into the overall evaluation of best interests. That is not the case here. Alta is not of an age, nor in a condition to have knowledge of and to adopt her parents' values, from which she could extrapolate a position on the complex issues that arise in this case.
>
> 96. In these circumstances, and absent *any* evidence to assist the court in determining the extent to which Alta would adopt wholesale the views of her parents, I am satisfied that the furthest the court can safely go in seeking to place itself in Alta's

> shoes is to acknowledge that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents. Within this context, I have held in mind at all times the strict religious credo that the parents adopt and the tenets of that credo as they relate to the withdrawal of life sustaining treatment. I have also borne in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that the court cannot simply assume that a profoundly disabled child will not wish to lead a life affected by disability. However, against these matters, I am satisfied that I must also have regard to the fact that Alta's likely attitude to treatment would be influenced by the fact that the prospect facing her if treatment is maintained is one of continued medical intervention that will do not more than maintain her in a moribund state with no awareness, with no prospect of improvement or recovery, the certainty of further physical deterioration and, as I have found above, in a situation of consistent pain. Within this context, in discharging the difficult task of asking myself what Alta's attitude to continued life sustaining treatment would be likely to be, I am satisfied that, in circumstances where she has not developed any understanding of the faith into which she was born, and giving due weight to the fact that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents, it is more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her."

42. The judge stressed that he had placed considerable weight on the fact that there is a strong presumption in favour of the preservation of life, but with this qualification (paragraph 98):

> "However, the sanctity of Alta's life is not, within the context of the secular laws that this court must apply, absolute. It may, on the facts of an individual case, give way to countervailing factors. In short, the presumption in favour of taking all steps to preserve life, whilst strong, is also rebuttable. That this is so recognises that life cannot be, and indeed should not be preserved at all costs."

At paragraph 99, he found that, in Alta's case, the fact that she is in consistent pain acts as a heavy counterweight to the presumption. Given his findings as to her experience of pain, he concluded that in her case it was a "very weighty factor" in the best interests analysis, particularly in the light of his finding that for as long as she survives she would accumulate further comorbidities that would increase the burden of pain. He also attached significant weight to the fact that the continuation of her current treatment would continue to place a significant burden on her without any prospect of improving her condition (paragraph 100).

43. The judge reached the same conclusion about the parents' proposal that Alta be transferred to Israel for continuing treatment. He observed (paragraph 101) that his evaluation of this issue had been "significantly hampered by a paucity of detailed

information" about this option, noting that the Israeli clinicians identified by the parents had not been available for discussions with the current treating team. Such information as he had was "a wholly insufficient basis" on which to conclude that the parents' proposal would be in Alta's best interests. Importantly, however, he added (at paragraph 102):

> "In any event, I am satisfied that even were there a detailed proposal for transfer available to the court, having regard to the court's findings with respect to Alta's experience of pain and to the courts findings as to her prognosis, it cannot be said to be in Alta's best interests to be transferred to Israel for life sustaining treatment to continue."

44. In addition, (at paragraph 103) he took into account the fact

> "Alta has and will continue to have minimal or no awareness of her family and social relationships, minimal or no ability to respond to external stimuli so as to take comfort or enjoyment from those who love her or the world around her and engage in the enlargement of knowledge of her world. "

He also took into account

> "the fact that continuing life sustaining treatment will confine Alta to being kept alive for the remainder of her life in a hospital room without windows, her life sustained by machines in a world she cannot meaningfully perceive or connect with."

45. The judge then considered the parents' views, informed as they are by their strong religious belief as Ultra-Orthodox Jews. He said that he had considered very carefully the evidence given by the parents themselves and by Rabbi Goldberg, whilst emphasising that

> "as would be the position were the court concerned with the religious principles observed by Christianity, Islam, Hinduism, Buddhism or any of the world's established religions, it is not religious law that governs the decision in this case but the secular law of this jurisdiction" (paragraph 105).

In those circumstances,

> "the question for the court is what outcome is in Alta's best interests taking into account *all* relevant factors, including the pain the court has found that Alta consistently experiences. Accordingly, the spiritual considerations that the parents urge upon the court fall to be considered alongside the very worldly issue of the consistent pain that the court is satisfied that Alta experiences … and the additional burdens on of treatment and her condition. Within this context, it is further important to note that, insofar as the parents' Article 9 right to freedom of thought, conscience and religion is engaged in this case and must be

> accorded weight (in respect of which I did not hear detailed argument) the right to freedom of thought, conscience, and religion may be circumscribed where this conflicts with the child's best interests." (paragraph 107).

He concluded (paragraph 108) that he was not satisfied that the strict religious principles which the parents hold outweighed the other, compelling, factors that point in the opposite direction in the best interests analysis.

46. On the parents' primary case, he therefore reached the following conclusion (at paragraph 109):

> "I am satisfied that the burden of Alta's underlying condition, generating as it does an experience of consistent pain for Alta and leaving her as it does in a state of perpetual darkness and silence, acts to overcome the benefits in sustaining her life. In the circumstances, and having examined Alta's best interests from a broad perspective, encompassing medical, emotional, sensory and instinctive considerations, and having paid due regard to the fundamental, but not immutable principle of the sanctity of life, as well as the parents' deeply held religious convictions, it is with deep regret that I am satisfied that it is not in Alta's best interests for life sustaining medical treatment to be continued and in her best interests for that treatment now to be withdrawn and to be moved to a palliative care regime."

47. Finally, he turned to the parents' secondary case – that Alta should be transferred to Israel for the withdrawal of medical treatment. He concluded that this would also not be in her best interests. Such a course would expose Alta to further pain and discomfort during the course of transfer for no medical benefit. He acknowledged that it would enable her to spend her last days with her family, that her death and burial would be in accordance with their religious beliefs, that her grave would be in Israel, and that, from the perspective of Jewish law, there would be spiritual benefits for her ending her life in that country. He was not satisfied, however, that what he described as "these necessarily adult concerns" could outweigh the additional burden of pain, particularly in circumstances "where, whilst not spiritually optimal, it is possible to transfer Alta for burial in Israel following her death in this jurisdiction". More fundamentally, there was no evidence that the course of action approved by the English court would be endorsed following her arrival in Israel, and that, notwithstanding the parents' assurance that they would respect the court's decision, it would not be surprising if that decision "were to be overborne by the siren call of friends and family".

The proposed appeal

48. The appellants seek permission to appeal and put forward the following grounds of appeal.

> (1) The judge erred in law and failed to apply the proper test of a child's best interests. He sought to apply uniform standards, rather than standards specific to this individual child.

(2) He failed to appreciate the overwhelming importance to this child of her religion and culture, and its strictures in relation to the withdrawal of medical treatment.

(3) He failed to appreciate the importance to this child of the duties of her religion including its strictures relating to death, and the customs requiring speedy burial alongside the auspiciousness of being buried in Israel.

(4) The judge's order wrongly interfered with Alta's rights to exercise the benefits of her Israeli citizenship. In making this order, the judge wrongly privileged the UK legal system over the rights that Alta enjoys under Israeli law.

(5) The judge misunderstood the medical evidence relating to the extent and nature of the pain experienced by Alta, and wrongly treated evidence that she suffers spasms and must therefore experience pain as meaning that she experiences pain that is so sustained and intense as to mean that she would wish to end that suffering by being caused to die.

(6) The decision did not properly take into account the interference with Alta's human rights under ECHR and the Human Rights Act 1998.

(7) The decision did not consider whether the decisions taken to withdraw treatment constituted indirect discrimination and further were prohibited breaches of the public sector equality duty and the provisions of ss.19, 20 and 149 of the Equality Act 2010.

(8) The judge wrongly rejected the parent's alternative plan for Alta, despite knowing that there would be evidence to substantiate the plans, and wrongly prevented them from being able to adduce additional evidence.

49. Following the hearing before the judge, the parents changed their legal representatives. Their case was presented on appeal by Mr Stephen Simblet QC with great clarity and sensitivity. In short, his argument was that the judge erred in law and fact in (1) his analysis of the degree and intensity of the pain that Alta is suffering and (2) his approach to Alta's religion and culture. As a result, his assessment of her best interests was flawed and his decision to make the declaration and orders sought by the local authority was wrong. All the grounds of appeal fall within, or are ancillary to, the issues of pain (ground 5) and religion or culture (the remaining grounds). I therefore propose to consider this application under those two broad headings.

50. Before doing so, however, there is a preliminary issue to be resolved.

Application to adduce fresh evidence

51. A few days before the hearing of the appeal, the parents' solicitor filed an application to adduce fresh evidence, consisting of:

(1) four statements from medical doctors;

(2) three reports relating to the transporting of Alta to Israel by air ambulance;

(3) a legal opinion on the religious principles, laws and cultural practices of Israel, and

(4) twelve letters from public figures in Israel and elsewhere, including the President of Israel, the Chief Rabbi of Israel, the President of the Board of Deputies of British Jews, and three US Congressmen.

At the hearing, we informed the parties that we would read the documents *de bene esse* and make a decision whether to admit them when considering the application for permission to appeal.

52. CPR 51.21(2) provides:

> "Unless it orders otherwise, the appeal court will not receive (a) oral evidence or (b) evidence which was not before the lower court."

It remains the practice of this Court to have regard to the principles set out in *Ladd v Marshall* [1954] 1 WLR 1489. To admit fresh evidence on appeal

(1) It must be shown that the evidence could not have been obtained with reasonable diligence for use at the trial.

(2) The evidence must be such that it would probably have an important influence on the result of the case.

(3) The evidence must be credible.

It is recognised, however, that in cases involving children, there is some scope for a more flexible approach:

> "there are an infinite variety of circumstances whose proper consideration in the best interests of the child is not to be trammelled by the arbitrary imposition of procedural rules. That is a policy whose sole purpose, however, is to preserve flexibility to deal with unusual circumstances. In the general run of cases the family courts (including the Court of Appeal when it is dealing with applications in the family jurisdiction) will be every bit as alert as courts in other jurisdictions to see to it that no one is allowed to litigate afresh issues that have already been determined" (per Waite LJ in *Re S (Discharge of Care Order)* [1995] 2 FLR 659 and p464, applied in *W v Oldham MBC* [2005] EWCA Civ 1247.)

Mr Simblet cited the decision of this court in *Singh v Habib* [2011] in which it was observed that the rule in *Ladd v Marshall* is "not a straitjacket".

53. In the present case, the parents, who were represented by experienced solicitors and leading and junior counsel throughout the proceedings up to and including the hearing before the judge, had the opportunity at the case management hearing on 29 January 2021 to request permission to obtain expert medical reports. They were granted permission to obtain a report from a respiratory physician, but did not ask for permission to obtain any other reports, for example from a paediatric neurologist. Instead, they elected to proceed by asking questions of the two independent doctors who had provided a second opinion before the start of proceedings, and of Dr B. In the

course of the hearing before this Court, Mr Simblet argued, somewhat faintly, that Dr Hart was not a fully independent witness, but I see no reason to doubt that the opinions expressed by both him and Dr Samuels were objective and independent of the opinions expressed by the Trust's clinicians. The parents had a fair opportunity to obtain and file expert evidence from a neurologist in accordance with the rules under Part 25 of the Family Procedure Rules (which governs the admission of expert evidence in children's proceedings) in good time before the hearing before the judge, but chose not do so.

54. The medical reports which the parents now seek to adduce are from four neurologists – three in the United States and one in Israel. Even allowing for the greater latitude to parties seeking to adduce fresh evidence in appeals concerning children, I conclude that none of these reports should be admitted. The first condition in *Ladd v Marshall* is plainly not satisfied, and in my judgment the second condition has also not been met. I recognise that the parents' new solicitor has had little time to prepare this application, but there has been no compliance with the requirements of Part 25. Mr Simblet submitted that in a case involving the life and death of the child, the court should not be constrained by those requirements. It seems to me that when a case involves such a serious issue, it is particularly important that the rules concerning expert evidence should be followed. All four reports are very short. Some of the doctors have seen some of Alta's medical records (but it is not always clear precisely which records); none of them has seen the expert evidence filed in the proceedings, nor, of course, examined the child. Given these deficiencies, in contrast to the very extensive medical evidence put before the judge in compliance with the rules, it is difficult to see how the new medical evidence which the parents wish to adduce could have any influence on the outcome of the appeal. Accordingly, I would refuse the parents' application for permission to adduce the four medical reports in support of the appeal.

55. I would also refuse the parents' application for permission to file the other documents. The statements from the air ambulance service and the Israeli medical institutions fill a gap in the evidence about which the judge remarked (at paragraph 101 of the judgment). For my part, it is unsurprising that the parents' representatives had been able to identify an air ambulance service willing to transfer Alta to Israel, or that there are several clinics in Israel with the highly specialised facilities required to care for the child, were an English court to decide that it is in her best interests to move to Israel. Once again, however, these statements could plainly had been obtained a good time before the hearing. In any event, in the light of the judge's observation at paragraph 102 of the judgment, it cannot be said that this evidence would probably have an important influence on the outcome of the appeal.

56. The Israeli legal opinion which the parents now wish to adduce is dated 6 May 2021. It was plainly in the possession of the previous legal team at least two weeks before the hearing at first instance. Indeed, leading counsel who represented the parents at the hearing before the judge informed him that it was in their possession when he enquired about the question of enforceability of an English order in Israel. The parents' current legal representatives have been unable to provide any explanation to this Court as to why their very experienced predecessors did not seek to adduce it at the hearing. It would be wrong to speculate about the reasons for this decision, but the consequence is that the first condition in *Ladd v Marshall* is not satisfied.

57. Finally, there are the letters from public figures in Israel and elsewhere. This Court has great respect for the views held by the President and Chief Rabbi of Israel and the other

correspondents. The issues arising in this case, as in similar cases in the English courts in recent years, have attracted extensive comment in this country and abroad. Such comment, from whatever source, cannot have an important influence on the outcome of proceedings, which must be determined on the evidence and in accordance with the principles of English law.

Pain

58. Mr Simblet's central submission under the fifth ground of appeal was that, since there is a strong presumption in favour of the course of action which prolongs life, the judge ought to have required particularly cogent evidence as to the unbearable nature of the pain which Alta is suffering before deciding that it was not in her best interests to continue to receive life-sustaining treatment. He contended that the judge's findings on this issue were incompletely reasoned and not supported by the evidence.

59. Mr Simblet conceded that the judge was entitled to prefer the evidence of Dr A and Dr Hart on this issue over the evidence of Dr Ross Russell. It was a feature of the case, however, that the nature and extent of the child's disability is so profound that objective measurement of pain is difficult. Mr Simblet attached considerable weight to the fact that, unlike some other cases including ***Raqeeb***, there had been no attempt to carry out a "Somatosensory Evoked Potentials" test which might have provided a more objective assessment of the functioning of the central nervous system. There was no evidence of the extent of the pain suffered by the child. The evidence showed that the words "pain" and "discomfort" were at times used interchangeably. Such evidence as was available indicated that the pain was not constant but, rather, a transitory reaction to a certain type of touch. Mr Simblet submitted that, having concluded from the evidence that she suffers regular spasms and therefore pain, the judge proceeded to make a further finding, without support, that this experience of pain was a "significant burden" and then elevated this to a finding of "consistent pain". Mr Simblet submitted that it was not legitimate to describe the transitory and separated painful events as amounting to "consistent pain".

60. Furthermore, Mr Simblet contended that the presence of pain, even if it is "consistent", should not be determinative of whether or not someone would choose to continue living. This was all the more important in the absence of any evidence that the pain suffered by Alta was acute or unendurable. In those circumstances, the judge's elevation of the pain that the child sometimes experiences into being effectively the decisive factor in the case was wrong. He wrongly equated incidents of intermittent pain with unendurable pain. In any event, the evidence about whether the child was suffering pain and if so to what degree was insufficiently cogent or serious to override the presumption in favour of preserving life.

61. Mr Simblet recognised that every advocate faces a significant challenge in seeking to persuade this Court to overturn a finding of fact made by a judge at first instance. In this case, with regard to the judge's findings about pain, Mr Simblet has fallen well short of meeting that challenge. The judge was presented with extensive and detailed evidence from the treating clinicians and independent experts about the pain that the child was suffering. He considered that evidence with conspicuous care and in meticulous detail. His finding that Alta suffered pain in response to particular touches or stimuli was fully supported by the evidence. Having read that evidence, I am satisfied that the judge's finding that the child suffers "consistent" pain is a fair description. The

pain is not constant but it occurs regularly, although not invariably, when she is subjected to certain stimuli. There is no prospect of an appellate court interfering with his findings about the causes of or degree of pain that Alta is suffering.

62. The judge rightly regarded the pain that the child is suffering, and will continue to suffer (possibly to a greater degree), as a very important factor in the welfare analysis. I do not agree with Mr Simblet's submission that the strong presumption in favour of preserving life can only be outweighed by "particularly cogent evidence" as to the "unbearable" nature of the pain the child suffering. I do not accept the submission that the evidence of pain in this connection has to be this "particularly" cogent. Evidence of pain in a patient with the degree of disability from which Alta suffers is often extremely difficult to obtain. Although the Somatosensory Evoked Potentials test was not carried out, the evidence put before the judge was detailed and coherent and plainly sufficient to support his findings.

63. Furthermore, I do not accept that pain has to be "unbearable" or "intolerable" for an application to withdraw treatment from a child to succeed. What is required is a balancing of all factors relevant to the child's welfare. Any significant degree of pain will be a factor to be weighed in the balance. Manifestly, the greater the likely degree and intensity of pain, the greater the weight it will be likely to carry.

64. There is no prospect of a successful appeal on the sixth ground.

Religion and culture

65. Mr Simblet's principal submission was that the judge's treatment of the issue of Alta's religion and culture was wrong in principle. He recognised that the parents' views, beliefs and culture were factors to be taken into account, and set them out at paragraphs 49 to 55 of the judgment. But in Mr Simblet's submission, the judge failed to attach sufficient weight to these factors. More fundamentally, he failed to treat Alta's religion and culture as an aspect of her own autonomy. He did not properly understand who Alta is, what her values and culture are and would become, and how those of her family, culture, wider religious community and citizenships are markedly different from the picture that he built of the child.

66. Mr Simblet framed his submissions by reference to an understanding of "who is Alta?" Although she was born in England, the more fundamental part of her identity is as a child born into a Hasidic Jewish family. Were she not a patient in a PICU, she, like the rest of her family, would live a very different life from most people in the United Kingdom. As far as possible, her family live within their own religious community, and minimise the extent to which they engage with the wider community and laws in the United Kingdom. Members of the community operate their own courts – it is not permitted for one of them to sue another in the courts of England and Wales. Any disputes within the community must be resolved by the rabbinical courts. Mr Simblet stressed, however, that although this is a reclusive community, and to that extent introspective, its members nevertheless have a somewhat international outlook, with travel between various groups being a natural part of their lives. Accordingly, Alta would normally expect to travel frequently to Israel, where she and her family also have citizenship, and to spend significant parts of her life in the profession and study of the Jewish faith. Within those mores, there are very different expectations of women and girls, and the life that Alta would expect to live is very different from the lives of other

children living in the locality. She would have much more in common with children (and more specifically, girls) born to Hasidic Jewish communities in other parts of England and elsewhere in the world.

67. For Alta's parents, practice of their religion is the centre of their lives. Precisely what this means is spelt out in the statements filed in the proceedings by Mr Fixsler and Rabbi Goldberg. Mr Fixsler spends his time when not looking after the family on full-time Torah study and his wife is employed as a teacher in one of the community's schools. In normal circumstances, the parents of any young child, especially a baby, would have almost complete control over the life of that child. They would choose her clothes, her diet, her religion, when she sleeps, when she is awake, where she goes, what she does and whom she sees.

68. Mr Simblet submitted that it is axiomatic that Alta's disabilities do not erase the separate components of her culture, religion and family's values. The fact that she has acute medical needs does not change who is, and ought to be, in day-to-day control of this baby's life. There would have to be compelling reasons to prevent a person from doing what her family wished her to do and are capable of providing for her. When set against the obligation to protect and preserve life, rather than to take it, the approach of the judge below was wrong.

69. Accordingly, Mr Simblet challenged the judge's analysis at paragraphs 95 and 96 of his judgment. Having in paragraph 72 rejected a submission that the "best interests decision-making process can and must be framed within the Jewish belief system in this case", he proceeded to reject the further submission that Alta would inevitably share the values of her parents, her brother and wider community. He concluded that Alta lacked the age and intellectual capacity to have taken on her religion. Mr Simblet acknowledged the artificiality (to which the judge referred at paragraph 95 of his judgment) of a judge trying to place himself into the shoes of a two year old child with brain damage. The judge failed to recognise, however, that this artificiality required a different evaluation. He found (in the last sentence of paragraph 95) that Alta was too young to have decided to follow her parents' and their community's values, which led him to the view (in paragraph 96) that the furthest he could go was to acknowledge that a child like Alta is often influenced by the values of her parents. Mr Simblet submitted that this approach to religion overlooks the fundamental nature of religion to this child, her family, her culture and her way of life. The judge misunderstood that in Alta's case, her religion is fundamental to her way of life and thus to her identity as a human being. Alta's religion and culture are part of her identity. It is not a matter of cognitive decision-making. Indeed, the absence of other life experiences and the ability to acquire those may make religion even more important rather than less. Essentially, the judge approached the issue from the perspective of a person looking for rational arguments in support of a religious belief, rather than being the birthright not just of Alta's parents but of Alta herself. He looked at this from the perspective of someone trying to decide the best interests of a standard child, rather than of this child.

70. Mr Simblet submitted that it was not correct for the judge to say that he was reaching his decision "absent *any* evidence to assist the court in determining the extent to which Alta would adopt wholesale the views of her parents". Given the circumstances of this family including Alta's elder sibling, it could be said with confidence that Alta would adopt her parents' views. In the circumstances, even though she has not developed any cognitive understanding of the faith into which she was born, the judge was wrong to

conclude that it was more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her. On the contrary, it was more likely that she would choose to suffer pain because religious and cultural views are integral to her identity.

71. In support of his submissions, Mr Simblet cited the observations of Baroness Hale of Richmond in Re J (A Child) [2005] UKHL 40; [2006] 1AC 80 (at paragraph 37-38):

> "37 … It would be wrong to say that the future of every child who is within the jurisdiction of our courts should be decided according to a conception of child welfare which exactly corresponds to that which is current here. In a world which values difference, one culture is not inevitably to be preferred to another….
>
> 38…. There is nothing in those principles which prevents a court from giving great weight to the culture in which a child has been brought up when deciding how and where he will fare best in the future. Our own society is a multi-cultural one…."

72. The Trust's application was for a declaration under the inherent jurisdiction and for a specific issue order under s.8 of the Children Act 1989. As a result, Mr Simblet acknowledged that it must be determined in accordance with the overall provisions of that Act. He submitted, however, that the relevant provisions included not only the principle in s.1(1) that the child's welfare is the paramount consideration and the welfare checklist in s.1(3) but also the provisions of s.1(2A) of the Act (inserted by the Children and Families Act 2014). S.1(2A) reads (so far as relevant to this submission):

> "A court, in all the circumstances mentioned in subsection (4)(a) … is as respects each parent within subsection (6)(a) to presume, unless the contrary is shown, that involvement of that parent in the life of the child concerned will further the child's welfare."

Subsections 1(4) reads (so far as relevant):

> "The circumstances are that:
>
> (a) the court is considering whether to make … a section 8 order, and the making … of the order is opposed by any party to the proceedings …."

Subsection (6) provides:

> "In subsection (2A) 'parent' means parent of the child concerned and, for the purposes of the subsection, a parent of the child concerned
>
> (a) is within this paragraph if that parent can be involved in the child's life in a way that does not put the child at risk of suffering harm; and

> (b) is to be treated as being within paragraph (a) unless there is some evidence before the court in the particular proceedings to suggest that involvement of that parent in the child's life would put the child at risk of suffering harm whatever the form of involvement."

73. Mr Simblet submitted that, as a result of s.1(2A), those making decisions about the medical care of a baby will, when the best interests criteria are being identified, attach particular importance to the bond between parent and baby and the fact that parents generally decide what their baby will or will not do. When considering any application under section 8, the court is required by s.1(2A) to proceed on the basis that "parental involvement" will further the welfare of the child, because the statute says so. In carrying out his evaluation of Alta's best interests, the judge failed to refer to s.1(2A) (and indeed to s.1(3)) of the Children Act, and failed to attach any or sufficient weight to the views of the parents, treating them as subordinate to the views of the doctors.

74. Mr Simblet emphasised that the importance which common law has always attached to the importance of individual self-determination and autonomy is now reinforced by the obligations placed on the hospital and the court, as public authorities, by s.6 of the Human Rights Act 1998, and in particular the positive duties under Article 8 of ECHR to protect a person's physical and psychological integrity (*Botta v Italy* [1998] ECHR 12), the right to freedom of religion and manifestation of that religion under Article 9, and the prohibition on discrimination under Article 14. Mr Simblet submitted that MacDonald J's judgment in this case failed to respect Alta's rights under Article 8, her rights and her family's rights under Article 9, and the enjoyment of those rights without discrimination on grounds of religion under Article 14. In his written submissions, Mr Simblet referred briefly to the seventh ground of appeal which asserted that the Trust's proposal and the judge's decision amounted to indirect discrimination and breaches of the public sector equality duty and other provisions under the Equality Act 2010. He contended that the effects of withdrawal of treatment on Alta, as opposed to on a baby who was not an adherent living the Hasidic Jewish faith, constitutes indirect discrimination on grounds of religion. It is a fundamental responsibility of the court to ensure there is no disadvantage or discrimination suffered by people who profess a particular religion.

75. In support of these submissions on human rights and discrimination, Mr Simblet cited the decision of the Divisional Court (Singh LJ and Whipple J) in *R (Adath Yisroel Burial Society and another) v HM Senior Coroner for Inner North London and another* [2018] EWHC 969 (Admin) in which the court declared unlawful and quashed a coroner's policy that "no death will be prioritised in any way over any other because of the religion of the deceased or family, either by the coroner's officers or coroners." The court found that the policy was unlawful because it fettered the coroner's discretion, was irrational, infringed the claimant's rights under Article 9, violated the principle of equal treatment under Article 14 read in conjunction with Article 9, and amounted to indirect discrimination under the Equality Act. The court held that a coroner cannot lawfully exclude religious reasons for seeking expedition of his or her decisions, including a decision whether to release a body for burial. Mr Simblet cited paragraphs 94 to 105 and paragraphs 113 to 125 of the judgment. He relied in particular on the dictum at paragraph 111:

> "What on its face looks like a general policy which applies to everyone equally may in fact have an unequal impact on a minority. In other words, to treat everyone in the same way is not necessarily to treat them equally. Uniformity is not the same thing as equality."

He also relied on the court's citation of the principle, derived from the jurisprudence of the European Court of Human Rights, that equality requires not only that like cases be treated alike but also that different cases be treated differently: *Thlimennos v Greece* (2001) 31 EHRR 15. Mr Simblet did not expand on this submission in the course of the hearing, nor did he elaborate on the contention also made in the seventh ground of appeal, that the judge failed to consider whether the decision taken to withdraw treatment was a breach of the public sector equality duty under s.149 of the Equality Act.

76. Finally, Mr Simblet developed the eighth ground of appeal, and the parents' secondary case that, if treatment is to be withdrawn, it would be in Alta's best interests to be transferred to Israel for that process to take place. Under the Trust's plan, Alta would die in this country, either in the PICU or in a hospice or at home, rather than in Israel. For members of her community, dying in Israel and being buried in accordance with Hasidic practices in that country is a matter of fundamental importance. Mr Simblet submitted that the parents had not had sufficient time to put together a plan and the judge unreasonably failed to allow them time to do so. The proposal was nevertheless put forward to the judge in the written submissions of counsel, but Mr Simblet contended to us that it received only very limited treatment in the judgment. He submitted that the judge failed to appreciate the importance to this child of the duties of her religion, including its strictures relating to death, and the customs requiring speedy burial alongside the auspiciousness of being buried in Israel. It was his case that the judge had been unduly swayed by his suspicion that, if allowed to travel to Israel, her future would then be reviewed and his decision that it was in her best interests for treatment to be withdrawn would be countermanded.

77. In his written submissions, Mr Simblet went so far as to suggest that the judge should have considered ceding jurisdiction to the Israeli courts, given that Alta is an Israeli citizen and, although resident in this country, is a member of a community which exercises its own dispute resolution system. Mr Simblet asserted that this raises issues both of conflicts of laws and jurisdiction, and potentially of international relations, where a court in this country uses its discretionary powers to make a decision that results in the loss of life of a citizen of another country. This was not an argument which he developed in his oral submissions. Indeed, he informed us that jurisdiction was "not in issue".

Further discussion and conclusions

78. The approach to be followed by a judge determining an application for an order authorising the withdrawal of life-sustaining treatment of a child is well established in the case law. The "intellectual milestones", as characterised by this Court in *Wyatt v Portsmouth Hospital NHS Trust* are as stated above:

(1) The judge must decide what is in the child's best interests.

(2) In making that decision, the child's welfare is the paramount consideration. The term "best interests" encompasses all welfare issues.

(3) The judge must look at the question from the child's assumed point of view.

(4) There is a strong presumption in favour of the course of action which prolongs life, but that presumption is not irrebuttable.

(5) The judge must conduct a balancing exercise in which all the relevant welfare factors are weighed.

79. When, as in this case, the matters before the court include an application for a specific issue order under s.8 of the Children Act, the court is required to have regard to the relevant welfare factors set out in the statutory checklist. It is the s.1(3) checklist that must be followed, not the factors set out in s.4 of the Mental Capacity Act. Although MacDonald J said as much in his judgment in *Raqeeb*, he did not in fact expressly refer to s.1(3) in his judgment in the present case. Having read his judgment, however, I am satisfied that he plainly had regard to all the factors in the checklist relevant to his decision.

80. As this case has demonstrated, the welfare checklist in s.1(3) is drafted in sufficiently broad terms to encompass all relevant factors. It includes the child's wishes and feelings (considered in the light of her age and understanding) and her background and any characteristics of hers which the court considers relevant. It also, of course, includes any harm that the child has suffered or is at risk of suffering.

81. The family's religion and culture are fundamental aspects of this child's background. The fact that she has been born into a devout religious family in which children are brought up to follow the tenets of their faith is plainly a highly relevant characteristic of hers. Under s.1(3)(d), the court is required to have regard to the fact that Alta is from a devout Hasidic family which has very clear beliefs and practices by which they lead their lives and that, if she had sufficient understanding, she too would very probably choose to follow the tenets of the family religion. I agree with Mr Simblet that this is a central part of her identity – of "who she is". It is unquestionably an important factor to be taken into consideration. But it does not carry pre-eminent weight. It must be balanced against all the other relevant factors.

82. None of the factors in the checklist has any presumption of precedence. The weight to be attached to each factor depends on the circumstances of the case and the final decision is that of the court. Whilst in an individual case the child's wishes and feelings, and her background and characteristics, including the religious and cultural values of the family of which she is a member, may attract particular weight, in all cases they start with an equal value to that of all the other relevant factors.

83. In support of the proposition that there is no presumption of precedence amongst the factors in the checklist, I cite one of the cases on which Mr Simblet relied – *Re J (A Child)* [2005] UKHL 40; [2006] 1AC 80. That case did not involve an issue about medical treatment. It concerned an application for the summary return of a child to Saudi Arabia under the Hague Child Abduction Convention. Unlike the present case, it involved parents from different cultural backgrounds who were in dispute about the future care of their child. Despite the differences between the facts of the two cases, the

observations of Baroness Hale are, as Mr Simblet recognised, relevant to the issues we have to decide. He cited parts of paragraphs 37 and 38 of Baroness Hale's judgment, but omitted the first two sentences of paragraph 38 which are in my judgment of particular relevance. Paragraph 38 reads in full as follows:

> "Hence our law does not start from any a priori assumptions about what is best for any individual child. It looks at the child and weighs a number of factors in the balance, now set out in the well-known 'check-list' in section 1(3) of the Children Act 1989; these include his own wishes and feelings, his physical, emotional and educational needs and the relative capacities of the adults around him to meet those needs, the effect of change, his own characteristics and background, including his ethnicity, culture and religion, and any harm he has suffered or risks suffering in the future. There is nothing in those principles which prevents a court from giving great weight to the culture in which a child has been brought up when deciding how and where he will fare best in the future. Our own society is a multi-cultural one. But looking at it from the child's point of view, as we all try to do, it may sometimes be necessary to resolve or diffuse a clash between the differing cultures within his own family."

The final sentence relates to the facts of that particular case and has no relevance for the present appeal. The preceding sentences, however, are highly relevant and provide clear confirmation that there is no presumptive precedence given to any of the relevant factors.

84. Mr Simblet's submissions come close to inviting the court to replace the best interests test with substituted judgment. He was, in effect, substantially repeating the argument put forward by counsel in *Raqeeb*, elevating the beliefs and values of Alta, as identified by the parents, to being the "key driver" of the court's best interests decision and giving those beliefs and values pre-eminent weight in the balancing exercise. Such an approach would be contrary to both case law and statute. The starting point must be the assumed point of view of the child, but that does not oblige the court to give the child's assumed views and beliefs pre-eminent weight in the analysis.

85. When considering the child's assumed point of view, it is difficult if not impossible to attribute any views, including religious beliefs, to a very young child who has never had, nor will have, any cognitive understanding. Tafida Raqeeb was a child developing normally until her devastating collapse shortly before her fifth birthday. In her case the judge (at paragraph 166 of the judgment) found on the evidence

> "that Tafida had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability"

although he was also satisfied that at the date of her collapse she would have had

> "no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises."

In contrast, in the present case Alta sustained very serious brain damage at birth and has never had the opportunity to learn anything about the religion and culture into which she was born.

86. I agree with MacDonald J's observation (at paragraph 123) in *Raqeeb* that

> "[given] the fact of evolving capacity, the sophistication of the values and beliefs of those children vary widely in accordance with their age and understanding, the concepts of thought, conscience and religion implying a developing capacity to understand, appreciate and engage rationally with competing ideas and beliefs and, ultimately, the fully formed capacity to exercise choice in respect of those ideas and beliefs."

In my judgment, the judge was entitled in the present case to refuse to assume that Alta would share the values of her family in circumstances where she never has had, nor ever will have, the ability to understand anything of the original culture into which she was born. As he said (at paragraph 95 of the judgment in this case) Alta is

> "not of an age, nor in a condition to have knowledge of and to adopt her parents' values, from which she could extrapolate a position on the complex issues that arise in this case."

In the case of a very young child in Alta's condition, the element of substituted judgment in the best interests decision is very limited and in this case is certainly outweighed by other factors, including in particular the fact that she is suffering consistent pain.

87. The views of parents about their child's welfare are plainly of great importance but, as repeatedly stressed in earlier cases (for example, this Court in *Wyatt v Portsmouth Hospital NHS Trust*), where there is a dispute between parents and clinicians about the serious medical treatment to be given to a child, it is the judge who must decide what is in her best interests. I am unpersuaded by Mr Simblet's reliance on s.1(2A) of the Children Act as in some way elevating the weight to be attached to the views of parents in such cases. The words of section 1(2A) do not support that argument. On behalf of the guardian, Ms Holloran drew our attention to the explanatory notes to the Children and Families Act 2014, which explained that the purpose of the new s.1(2A) was

> "[i]n respect of private family law (by which is meant the law about resolving disputes between family members, as distinct from public family law, about intervention by public authorities) … to send a clear signal to separated parents that courts will take account of the principle that both should continue to be involved in their children's lives where that is safe and consistent with the child's welfare, which remains the court's paramount consideration."

That submission is supported by the language of section 1(6), which defines 'parent' for the purposes of section 1(2A). I do not consider that s.1(2A) has any relevance to the issues before the judge which were between the parents and a public authority (the Trust). It adds nothing to the parents' case. It is in any event axiomatic that as a general

rule the involvement of parents in the life of a child will further the child's welfare. In most situations, decisions about a child's life are a matter for the parents without any interference by a court. But where a dispute arises between parents and doctors about the treatment to be given to a child, and the court is asked to make a decision, it is the role and duty of the court to do so and to exercise its own independent judgment. The views and wishes of the parents will always carry weight, in most cases very considerable weight, but the decision as to what course is in the child's best interests must be taken by the court.

88. Returning to the judge's analysis, I am entirely satisfied that he was entitled, and right, to conclude that it is in Alta's best interests that the life-sustaining treatment be withdrawn. In reaching that conclusion, he took as his starting point the assumed point of view of the child (paragraphs 95 to 96); placed considerable weight on the strong presumption in favour of taking all steps to preserve life (paragraph 97); nevertheless concluded that her experience of pain was "a very heavy counterweight to the presumption" particularly given the likelihood that it would increase (paragraph 99); took into account the fact that continuing the treatment would impose an additional burden on her (paragraph 100); took into account that because of her condition she would have minimal awareness of family and social relationships and as a result have minimal or no ability to take comfort or enjoyment from those who love her or were around her (paragraph 103); carefully considered the religious views of principles held by her parents (paragraph 106), but concluded (paragraph 108) that he was not satisfied in the circumstances of this case that those beliefs and principles outweighed the other compelling factors that pointed in the opposite direction.

89. I have already said that I would dismiss the fifth ground of appeal relating to the issue of pain. Subject to one qualification, there is no merit in the remaining grounds nor in Mr Simblet's criticisms of the judgment. For the reasons already explained, I do not agree with the contentions in the second and third grounds of appeal that the judge did not properly understand who Alta was, or that he failed to appreciate the importance of religion and culture to her family and to her, or the significance of the strictures relating to death. Although it was not strongly pursued before us at the hearing, I reject the argument encapsulated in the fourth ground of appeal that the judge "wrongly interfered with Alta's rights to exercise the benefits of her Israeli citizenship" or that he "wrongly privileged the UK legal system over the rights that Alta enjoys under Israeli law". I recognise and respect the Hasidic custom of resolving disputes within the community but an issue between an individual and a public authority must be determined under the laws of this country and by its justice system. Alta is habitually resident in England and Wales, is subject to the law in this jurisdiction, and is entitled to the protection it affords her.

90. Contrary to the sixth ground of appeal, I have no doubt that the judge took into account Alta's human rights. I agree with Ms Mulholland's submission on behalf of the Trust that the careful analysis which the judge undertook implicitly addressed the relevant Convention rights, that he expressly considered rights arising under Article 9 and that, insofar as there is a conflict between the family's rights and Alta's best interests, it is her best interests which must prevail. Furthermore, there is no merit in the argument raised in the sixth and seventh ground of appeal that the decision did not consider whether the withdrawal of treatment constituted discrimination contrary to article 14 or indirect discrimination under the Equality Act, or an infringement of other provisions

under that Act. The Trust and the court are not treating Alta differently or less favourably than others because of her religion, nor are they applying any provision, criterion or practice which is discriminatory in relation to her religion. Ms Mulholland submitted that the comparison drawn with the *Adath-Yisroel Burial Society* case is erroneous. She argued that, whereas that case concerned a policy adopted by a coroner which, when applied, indirectly discriminated against the Jewish community, in the present case there is no policy in play but rather a difference of opinion on how Alta should be treated which gave rise to an application on the part of the Trust – an application which it was duty-bound to make. I agree. It is obviously right that to treat everyone in the same way is not necessarily to treat them equally, and that different cases should be treated differently, but those maxims have no relevance to this appeal. Alta was not treated by the court in the same way as every other child. Instead, the judge was evaluating *her* best interests having regard to all the factors relevant to *her* welfare. Contrary to Mr Simblet's submission, the judge did not approach the issue from the perspective of someone deciding the best interests of "a standard child". At all times, his focus was on the best interests of *this* child.

91. I do not accept the parents' eighth ground of appeal, that the judge wrongly rejected their alternative plan to take Alta to Israel for the withdrawal of treatment to take place, despite knowing that there would be evidence to substantiate the plans, and wrongly prevented them from being able to adduce additional evidence. The judge recognised the importance of the family's religious beliefs and customs and the particular significance attached to customs concerning death and burial. His reasons for rejecting the secondary plan were essentially threefold:

(1) that the act of transferring Alta to Israel for the withdrawal of treatment would cause her further pain and suffering;

(2) that it would be possible for her body to be taken to Israel following death in this country;

(3) that there was a risk that, once she was transferred to Israel, the decision of the judge that her treatment should be withdrawn would be reversed, contrary to her best interests.

In my judgment, he was entitled to reject the parents' proposed secondary plan for these reasons.

92. It follows that there is no prospect of a successful appeal on the proposed grounds 2 to 8. I would therefore refuse permission to appeal on those grounds.

93. The one part of the judge's analysis about which I have had some doubt is the concluding part of paragraph 96. In my view, it was neither necessary nor possible for the judge to conclude that "it is more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her". Given her age and lack of understanding, I think it is impossible to reach any conclusion as to what her views would be. For that reason, I would, if my Ladies agree, grant permission to appeal on the first ground of appeal in which it is asserted that the judge failed to apply the proper test of a child's best interests. But that criticism of one aspect of the judge's reasoning does not, in my view, undermine his overall analysis or his ultimate conclusion. A careful reading of the judgment demonstrates that the judge applied the

proper test of a child's best interests and that he reached his decision by focusing on the circumstances of this child. Having granted permission to appeal on the first ground, I would therefore dismiss the appeal on that ground.

94. I know that Alta's devoted parents will be profoundly distressed by the outcome of this appeal. Every parent and grandparent – indeed every person – from every community will have the deepest sympathy for them, and for Alta's loving sibling. The strong support they draw from their faith and their community will be a source of consolation, but the emotional pain they are suffering is very hard to endure. I understand why they have pursued this appeal and deeply regret that I cannot do more to help them. As a judge, however, my duty is to apply the law, and in this case, the law requires me to dismiss the appeal for the reasons I have given.

LADY JUSTICE CARR

95. I agree.

LADY JUSTICE ELISABETH LAING

96. I also agree.