

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 19 August 2015

Before :

SIR JAMES MUNBY PRESIDENT OF THE FAMILY DIVISION

In re Jake (A Child)

Mr Conrad Hallin (instructed by DAC Beachcrofts) for the applicant NHS Foundation Trust
Mr Richard Ager (instructed by Bosley & Co) for the father
Mr Joseph Railton Stanger (of Railton Solicitors, instructed by the Official Solicitor as
litigation friend) for the mother
Ms Jacqueline Roach (instructed by the local authority legal services) for the local authority
Ms Lucinda Davis (instructed by Chamberlain Martin) for the guardian

Hearing date: 29 May 2015

Judgment

Sir James Munby, President of the Family Division :

1. On 29 May 2015 I heard an urgent application relating to the medical treatment of a gravely ill 10-month old child. Because the matter arose during the vacation, was urgent and was not, in the event, contentious, the hearing, which lasted for about 90 minutes, took place by telephone conference call. In accordance with the usual arrangements, the hearing was recorded and the proceedings have subsequently been transcribed, though only after some delay. At the end of the hearing, I indicated that, subject to certain amendments, which in the event were agreed, I proposed to make an order in the terms sought. The precise terms of the order were finalised later the same day. It is set out in an Annex. I now give my reasons for making that order.
2. I am very sorry that this judgment has been so delayed. Most of it, in fact, was prepared within days after the hearing. Accordingly, except where otherwise noted, the facts are set out, using the present tense, as they were at the date of the hearing.

The background

3. Jake was born in July 2014 and is thus some 10 months old. He is the much loved child of his parents, who are devoted to him and understandably deeply distressed by their son's condition and the agonising situation in which they all find themselves. Both parents have their own difficulties, each having a diagnosed learning disability.

Father's FS IQ is assessed at 61, mother's at 60. Father has capacity to litigate, the mother does not.

4. The local authority began care proceedings in relation to Jake in August 2014. The proceedings were issued in the Family Court. An interim care order was made at the case management hearing a few days later. The only relevance of this for present purposes is to explain the involvement of the local authority in the proceedings before me. For the effect of the interim care order is, of course, that the local authority shares parental responsibility for Jake in accordance with section 33(3) of the Children Act 1989.

Jake's medical problems

5. For much of his short life, Jake has been in hospital. He was admitted in September 2014 as he was having seizures. He remained in hospital until 11 December 2014, when he was discharged into the care of foster carers. On 2 March 2015, he was unresponsive when his foster carer tried to wake him, although his breathing appeared normal. On waking, he had a prolonged seizure. He was admitted to hospital again. Nine days later, on 11 March 2015, he was transferred to the London Teaching Hospital where he had spent much of the time the previous year and where he remains. Since October 2014 Dr W has been the consultant paediatric neurologist there responsible for his care. She has 12 years consultant experience. She works mainly in the complex epilepsy service, investigating and managing the medical needs and epilepsy of children like Jake.
6. I have three accounts from Dr W of Jake's difficulties: a medical report dated 4 May 2015, a medical report dated 21 May 2015, and a witness statement dated 28 May 2015. They should be allowed to speak for themselves. So I quote from them extensively.

Jake's medical problems: Dr W's first report

7. I start with the report dated 4 May 2015. Dr W diagnosed Jake as follows:

“Jake has an **epileptic encephalopathy of infancy** which in my view, is almost certainly genetic. A large number of tests have been done to try and find the cause of Jake's epilepsy and other problems. So far many results have been normal. I have this week received a genetic result which may be important but which needs some further exploration (I have asked blood from both parents to be tested) in order to understand what it may mean for Jake and his parents. I have also made a referral to Dr J, Consultant Clinical Geneticist, who will help to interpret the results from Jake and both parents when they become available in a few weeks time.”

8. Dr W described Jake's medical problems as follows:

“1 **Epilepsy** with frequent epileptic seizures which so far occur many times each day and cannot be controlled with medication.

2 **Movement disorder** affecting his whole body so that Jake cannot control his movements well. He wriggles uncontrollably when he is awake. He sometimes gets distressed with the movements. Jake's father has asked whether Jake has cerebral palsy. **Cerebral Palsy** is a term used to describe lots of different kinds of movement problems which start in early childhood and are not progressive. Jake probably does have a form of cerebral palsy (I would use the term dyskinetic cerebral palsy meaning lots of additional involuntary movements rather than stiffness which is more common). I think he will always have difficulties with controlling the movements of his body.

3 **Unsettled and unpredictable sleep pattern**

4 **Gastrostomy (tummy tube for feeding)**. Jake cannot take enough food by mouth safely and without choking so that he can grow. At the moment, it is not safe for Jake to have milk or food by mouth. A Speech and Language therapist will assess him from time to time when he goes home, as swallowing can sometimes improve. It is unlikely that Jake will be able to manage without the help of a gastrostomy tube in the long term.

5 **Developmental delay**. Jake has not made the developmental progress we would expect. I think that whatever genetic problem is causing the seizures is also the cause of his developmental delay. His delay cannot be explained by just the seizures or by his medication. He is severely delayed. We cannot be sure how much he can see or hear. He does not smile but is comforted with cuddles and physical contact.”

9. Describing Jake's current and likely cognitive abilities, Dr W said:

“Jake has made little developmental progress. He is very likely to have a significant learning disability in the future. He may never walk or be able to communicate with words. His vision also may be affected because his brain cannot make sense of what his eyes see. His developmental progress has been assessed by the team at ... and they will continue to monitor his progress when Jake leaves hospital.”

Explaining the likely impact of seizures on his development, Dr W said:

“Jake's delayed development cannot be explained solely by his seizures. Although improved seizure control would be expected to lead to some developmental gains, I suspect any gains will be very slow. As time goes on, his developmental potential will become easier to predict. However the fact that Jake made no significant developmental progress between hospital admissions and whilst in foster care is of concern.”

10. Dr W then turned to consider Jake's life expectancy. She said: "Jake's life is likely to be shortened because of his medical problems. There are no good studies of life expectancy in children exactly like Jake." Having examined the literature she continued:

"Jake is in a higher risk group compared with most children with epilepsy.

A trend is seen with younger children with complicated epilepsy (that is epilepsy with significant intellectual disability or a known structural brain lesion) diagnosed early having a shorter time to death ... Published data are lacking, but experience suggests that the mortality in some genetic epilepsy syndromes such as Dravet Syndrome approach 20% by the age of 5 years, Ohtahara's syndrome 70+% by the age of two years. In my view, the severity of Jake's epilepsy and neuro-developmental status is such that a prediction of life expectancy is likely to fall somewhere between Dravet and Ohtahara syndromes."

11. Dr W then set out the treatment plan for Jake:

"Goals of treatment are to minimise the impact of the epileptic seizures and movement disorder so that Jake is not distressed by them, is able to maintain his airway, blood pressure and blood oxygen levels as well as possible, and to minimise any harm or side effects caused by medication or other treatments. A number of different epilepsy medications have been tried without success to date and dietary treatment started last week in an effort to improve seizure control and be able to reduce Jake's medication. Further medications may be tried in the future. Jake's father has requested I ask for a second opinion from my neurology colleagues at Great Ormond Street Hospital with regard to diagnosis, prognosis and treatment plans. I have made the referral.

... Currently Jake will be given full medical support including cardio-respiratory resuscitation, intubation and ventilation should his condition deteriorate. However if after review by the medical team and discussion with multidisciplinary colleagues and those with parental responsibility, it is considered that further intervention would be futile or harmful, such medical interventions may be limited. Treatment decisions are discussed in an ongoing way with those holding parental responsibility and as far as possible the views of Jake's parents and all carers are considered."

12. I need not refer to the remainder of the report.

Jake's medical problems: Dr W's second report

13. Dr W's second medical report, a little over a fortnight later, is dated 21 May 2015. She described it as being updated in the light of the recent deterioration in Jake's medical condition. She described his current medical condition as follows:

“Jake has continued to have seizures and abnormal movements episodically many times per day. He is currently being nursed in a high dependency environment next to the nurses' station on our children's neurology ward. When he is settled and asleep, he has pink lips, his breathing is regular and his heart rate and blood pressure are normal. When he is disturbed or wakes, Jake wriggles immediately and the movements of his arms and legs are uncontrolled and involuntary. He seems to be comforted when his parents speak to him or stroke him. He often has more violent movements with twitching of his face which we think are probably seizures. Over the past 5 days Jake has stopped breathing with these sometimes. He has also had pauses in his breathing without obvious seizures. At the beginning of this week, these episodes would recover quickly with some extra oxygen given through a mask and some tickling or gentle poking. Yesterday Jake needed extra help when his breathing stopped and his lips turned blue – he needed bag and mask ventilation on several occasions. Today he has again needed this help but his heart rate has also been very slow at times with these seizures.

Jake has not been tolerating any milk or liquids through his gastrostomy. He has been on intravenous fluids since Wednesday.

There are no signs of an intercurrent illness. We have not identified a treatable cause for this worsening in Jake's neurological condition.

We are continuing to treat seizures with rescue medication and ongoing antiepileptic drug therapy is being given intravenously. He has been started on a clonidine infusion to replace the Clonidine which had been being given through the PEG to help with the involuntary movements. He was started on antibiotics earlier this week.”

14. Dr W then described the proposed treatment if Jake remains stable or his condition improves:

“I plan to continue antiepileptic drug treatment with phenytoin/leviteracetam and movement medication clonidine. Medication is likely to be adjusted from time to time. It is extremely unlikely that involuntary movements or seizures can be controlled, given the drug resistant nature of these symptoms to date. The goal of medical treatment is therefore to provide

symptom control as far as possible, limiting the impact of seizures/movement disorder on Jake's wellbeing."

15. Dr W then turned to describe the proposed treatment if Jake's condition continues to deteriorate. She identified three options, Option A, Option B and Option C, describing them as follows:

"Option A – Palliative Care / End of Life Care

To continue to treat epilepsy and movement disorder with regular medication given intravenously.

To re-establish feeding through PEG if his condition allows

To only treat movements with rescue medication when Jake is clearly distressed or cannot sleep

To limit escalation of breathing support to facial oxygen only and not to escalate or call CRASH team. This would be called a 'DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION' or 'DNACPR'

If feeding cannot be re-established and if necessary provide epilepsy/sedation medication through a subcutaneous pump so that the dose can be titrated to control Jake's symptoms and keep him comfortable.

To nurse Jake in a quiet room where parents and family can remain with him, hold and look after him, and visiting hours are unrestricted.

Jake may die over the next few days but he may survive.

Option B – Full Resuscitation and PICU support if necessary

To continue to treat epilepsy and movement disorder with regular medication given intravenously or until PEG feeding can be re-established

To re-establish feeding through PEG if his condition allows

To treat movements with rescue medication when Jake is clearly distressed or cannot sleep

To escalate support for breathing difficulties, heart rate abnormalities and low blood pressure including full cardiopulmonary resuscitation, intubation and ventilation.

Option C – Limited resuscitation and PICU support

To continue to treat epilepsy and movement disorder with regular medication given intravenously or until PEG feeding can be re-established

To re-establish feeding through PEG if his condition allows

To treat movements with rescue medication when Jake is clearly distressed or cannot sleep

To escalate support for breathing difficulties to include respiratory support (intubation and ventilation) for a limited time, but not cardiac compressions, DC shock or ionotropic drugs.”

16. Each of these options was accompanied by a tabulation of benefits and burdens, some relating to Jake and some to his parents. So far as Jake is concerned, Dr W identified one of the benefits of Option A as being “No painful procedures.” The benefit of Option B was that “Jake may survive and not be ventilator/airway dependent.” The burdens were listed as follows:

“Painful procedures including intubation, insertion of venous and arterial cannulae

Risk of pneumonia and multi-organ failure consequent on ongoing seizures which cannot be controlled

Risk of death despite all medical support ...

If Jake survives, he may be difficult to extubate, require a tracheostomy and/or require re-intubation within a short timeframe because of the underlying neurological condition, ongoing seizures, intercurrent illnesses or effects of medication”

The same burdens were identified in relation to Option C.

17. Dr W’s prognosis was as follows:

“Jake is both life limited and life threatened as a consequence of his underlying neurological condition. I would not expect him to survive early childhood, recognising that some children do survive longer than we expect given the severity of their symptoms.

Death in the next few days or weeks or months would not however be unexpected, whichever course of treatment is followed.”

18. Dr W concluded with the proposed treatment:

“I have discussed the treatment options with colleagues in the neurology department, palliative care team, PICU and with

members of the senior nursing team. We are agreed that care should be limited to Option A as attempts to prolong Jake's life in the event of a prolonged apnoea or cardio respiratory arrest are highly likely to be futile.

I have also discussed this today with both parents ... I believe they understand that Jake is very ill and that he has got worse day by day this week. They have seen that his breathing stops and witnessed bag and mask ventilation ... ”

Jake's medical problems: Dr W's witness statement

19. Dr W's witness statement is dated 28 May 2015. She records that Professor S, Consultant Paediatric Neurologist at Great Ormond Street Hospital, provided a second opinion regarding diagnosis and management on 12 May 2015.

“He met Jake and was able to review his medical records and investigation results. From a diagnostic perspective he had no additional investigations to suggest apart from considering a repeat Brain MRI. This is likely to require a general anaesthetic and since then Jake has been too medically unstable for this. We are currently exploring the option of performing a very limited Brain MRI without the need for GA. It was Prof S's view that further imaging was unlikely to offer diagnostic information but may provide additional information regarding brain growth (or lack of) which would possibly help the family to understand the progressive nature of Jake's underlying condition. From a management perspective, Prof S felt that regular epilepsy medication should be minimised in order to reduce potential side effects, and that seizures should not be aggressively managed unless life-threatening.”

20. Dr W then provided an updated account of Jake's condition:

“Since preparing my initial report ... , Jake's condition has deteriorated. I refer to my medical report dated 21 May 2015 which sets out how this deterioration originally manifested itself. Since that time there has been further deterioration in Jake's condition. On Saturday 23 May a Midazolam infusion was started because of seizures which were becoming more frequent, more prolonged and often associated with apnoea requiring bag and mask ventilation for short periods. Jake was also vomiting frequently and his gastrostomy feeds were discontinued. His medications were adjusted to be given intravenously (necessitating the insertion of a peripheral cannula) so that he is now receiving both Midazolam and Clonidine (a movement disorder and sedative drug) via continuous infusions.”

21. She continued:

“The Trust is concerned that Jake has a progressive underlying condition because of his increasing symptoms and an increasing burden of medical treatment (more medications at higher doses and given more invasively) at a very young age. His life expectancy is further reduced in the light of this continued clinical deterioration, in particular the need for bag and mask ventilation at times. Although seizures and abnormal movements have settled over the past three days, this is very unlikely to be sustained in the longer term. Jake’s condition is unpredictable and an acute deterioration could occur at anytime necessitating escalating treatment that the team believe would not be in Jake’s best interests because it would be invasive, potentially painful, burdensome and is not going to cure Jake’s underlying condition or improve his quality of life. As a result, and due to the fact that there could be an imminent deterioration at any time, the clinical team believes that it is necessary to make this application as a matter of urgency.”

22. Dr W then described her discussions with Jake’s parents and two grandmothers, including, importantly, a meeting on 27 May 2015 when the parents’ advocates were there to support them. The note of that meeting records that:

“[Jake’s father] asked ‘how do you expect us to make this decision’ and Dr W acknowledged how hard this is and that sometimes the decision does not have to be made by the parents but instead may be made by a judge in court or with social services. Jake’s parents do not want social services to make the decision.”

Dr W went on in her witness statement:

“In summary, [his parents] understand the severity of Jake’s condition but are hopeful he will get better. I told them that we are all working together to ensure that everyone has the chance to think carefully about Jake and how best to treat him. They love him very much and would want him to live, but they do not want him to suffer and would like to be able to spend more time with him. I informed them that I believed Jake had been stable for 1-2 days only because he was on the infusions and that we couldn’t keep the infusions going for a long time ... I discussed the possible options for medical care as I see them, giving potential benefits and burdens of each as given in my report dated 21 May. [The parents] have discussed resuscitation together and have come to the conclusion that they do not want Jake to have a tube in his throat or to be put on a life support machine if he were to ‘Crash’, because those procedures would be uncomfortable or painful. They do not want Jake’s heart to be restarted with ‘the paddles’.”

23. The relief being sought by the hospital had, I was told, been the subject of careful discussion between Dr W, her team and the lawyers. In her witness statement Dr W identified various contingencies and set out her opinion as to what would be appropriate:

i) **In the event of a serious deterioration in Jake's medical condition** it would be in his best interests to withhold: (a) bag and mask ventilation, save to the extent that it is considered to be clinically appropriate in any given situation; (b) endotracheal intubation; and (c) invasive or non-invasive ventilation. Dr W described the justification for this as being that:

“such treatment is invasive, potentially painful and would be burdensome and futile in the face of imminent death or inevitable demise.”

ii) **If Jake were to have a cardiac arrest** it would be in his best interests to withhold cardiac massage and resuscitation drugs including inotropes. Dr W described the justification for this as being that:

“such treatment is invasive, potentially painful and would be burdensome and futile in the face of imminent death or inevitable demise.”

iii) **If Jake were to have a serious infection, including pneumonia** it would be in his best interests not to undergo blood sampling or to receive intravenous antibiotics unless it is considered that such treatment would help to make him more comfortable and/or distress and pain free. Dr W described the justification for this as being that:

“Jake would face prolongation of life with the burden of frequent seizures and disabling movement disorder due to the underlying condition, together with lack of ability to derive benefit from treatment. He is severely developmentally delayed and the degree of cognitive impairment will not be significantly improved even if seizures and involuntary movements are controlled.”

iv) **In the event of a significant deterioration in Jake's absorption of enteral nutrition** it would be in his best interests to withhold parenteral nutrition. According to Dr W:

“this would require the insertion of a long intravenous line or Hickman line which may need general anaesthesia for placement, would inevitably increase the risk of infection and in the very long term might be associated with additional liver impairment.”

v) **If Jake becomes severely distressed and/or he is in pain due to further deterioration of his medical condition** it would be in his best interests to receive pain medication (such as Morphine) and/or sedation (such as Midazolam) in order to relieve his suffering and/or distress even though this

might reduce his respiratory drive and, if in an end of life situation, might shorten his life. According to Dr W:

“both parents and the clinical team looking after Jake believe that Jake’s comfort is most important.”

The parties’ positions

24. Dr W’s medical reports and evidence were not challenged by anyone, though a few questions were asked of her during the hearing by way of clarification of two matters: first, who, on the ground, would be taking the decisions were the declarations to be granted; and, secondly, whether what was proposed, in the event of a cardiac arrest, was discretion to use five rescue breaths or not to use bag and mask ventilation at all. Her response to the first question was that where possible it would be a joint decision, after discussion with all the team members. Her answer to the second question was that this was what was proposed.

25. The relief being sought by the hospital was not opposed by anyone. Mr Conrad Hallin, on behalf of the hospital, had prepared a detailed position statement, including a valuable analysis of the relevant legal principles which, he submitted, in the light of Dr Ws evidence justified my making the order sought.

26. Jake’s father, who was present throughout the hearing, was represented by Mr Richard Ager. His position was set out, very simply and very clearly, in a position statement prepared by Mr Ager:

“He loves his son absolutely, is highly distressed concerned and worried for his welfare and wants the best that can be done for Jake in his extreme position ... In conference on 25 May, [he] considered that Option A is in Jake’s best interest considering that the disruption pain and distress that could be caused to Jake by the crash team intervening outweighed any benefit ... [At] the meeting at the hospital [on 27 May 2015] this remained his position.”

27. Jake’s mother was represented by Mr Joseph Railton-Stanger. During the hearing he was able to take further instructions from her by telephone. The transcript records what he told me:

“What she reiterated again to me today in terms of her wishes and feelings is, firstly, that she thinks that Jake is a fighter and she wants him to survive. Her dearest wish is that he does survive. She does not want Jake to have any pain or suffering and she wants him to be as comfortable as possible.

It is a concern for [her] that she is with Jake as much as she can be ...

She would very much like there to be perhaps a room arranged in the hospital that she and father can perhaps spend the night in so that someone would always be there to be able to be with

Jake if the other parent was asleep. She is clear that she has indicated, in terms of treatment (and I am aware of Dr W's capacity certificate in respect of [her] understanding of the subtleties of different treatments), that she does not want Jake to be placed on what she calls "the breathing machine", which is the ventilator; and that she would not want him to have to be placed on "the electric machine", which is what she calls that, to start Jake's heart. Or to receive the hand-CPR, because she says that would hurt him. So that is what she said today."

28. I should, I think, repeat a comment that I made at that point:

"If I may say so, it is a very illuminating illustration of how somebody who has [the mother's] limitations nonetheless understands the fundamentals here. We all know what she means when she refers to "the breathing machine" and "the electric machine", and that shows that she understands the fundamental issues and is able to express a very clear view about it, which is an entirely understandable and indeed appropriate view."

29. I added that "In terms of simple humanity, parents must have as much time as they want, not least because it may be a distressingly short time, with their much loved baby."

30. The local authority was represented by Ms Jacqueline Roach. Her position statement helpfully distilled the relevant legal principles. She set out the local authority's position as follows:

"I am instructed to confirm that the Director of Children Services has carefully considered the medical report and in all the tragic circumstances of this case, with deep sadness and sympathy for Jake's parents, he accepts and agrees with the recommendation of the medical team.

The authority note the discussions with Jake's parents and are keen to ensure that they get all the support they need at this difficult time.

... . Option A is geared towards palliative/end of life care. The hospital favours Option A as the least burdensome option for Jake and his family. The local authority would agree with this analysis.

... The local authority acknowledges how deeply sad and traumatic the decision before the court must be for the parents and will continue to support the parents spending time with Jake."

31. Picking up the point which Jake's parents had made at the meeting on 27 May 2015, Ms Roach said:

“The local authority would like to re-assure the parents that even if such a course were sanctioned, which it is not, local authority would not place itself in the position of making such a grave decision for Jake and indeed is not able to consent to a declaration even though the local authority shares parental responsibility with the parents. The local authority is clear that in a situation such as this it is up to the court to make the decision as to Jake’s treatment on the basis of an application from the hospital.”

32. Jake’s guardian was represented by Ms Lucinda Davies. The guardian’s position, as set out in her position statement was that she supported the medical treatment plan for Jake as being Option A.

The law

33. The law is reasonably clear and settled. Subject to one important qualification I can take it from the judgment of Peter Jackson J in *Re KH (Medical Treatment: Advanced Care Plan)* [2013] 1 FLR 1471, which was itself in large measure based on the summary of principles set out in the judgment of Holman J in *An NHS Trust v MB (A Child represented by Cafcass as guardian ad litem)* [2006] EWHC 507 (Fam), [2006] 2 FLR 319, para 16. There is no need for me to add to the jurisprudence.
34. Peter Jackson J referred (para 17(11)) to the Royal College of Paediatrics and Child Health’s publication, *Withholding or Withdrawing Life Sustaining Treatment in Children: A Framework for Practice*, second edition, May 2004. This has now been superseded by the third edition, published in March 2015, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*, Larcher V, et al, Arch Dis Child 2015; 100(Suppl 2):s1–s23. The passage which is relevant for present purposes is section 3.1.3, *Situations in which it is appropriate to limit treatment*.
35. Section 3.1.3 begins as follows:

“The underlying ethical justification for all decisions to withhold or withdraw LST [Life-Sustaining Treatment] is that such treatment is not in the child’s best interests. There are three sets of circumstances where it may be appropriate to consider limitation of treatment.”

Those three sets of circumstances are then considered under the headings *Limited quantity of life*, *Limited quality of life: where there is no overall qualitative benefit*, and *Informed, competent, supported refusal of treatment*. The third does not arise here, so quotation is confined to the other two. I set them out in an Annex. It will be seen that the discussion differs significantly from, and is considerably longer than, the corresponding passage in the previous edition.

Discussion

36. Mr Hallin submits that, were Jake to suffer a very serious deterioration, the case would fall within section (C) of the discussion under the heading *Limited quantity of life*:

“Inevitable demise

In some situations death is not imminent (within minutes or hours) but will occur within a matter of days or weeks. It may be possible to extend life by treatment but this may provide little or no overall benefit for the child. In this case, a shift in focus of care from life prolongation per se to palliation is appropriate.

In both ‘Imminent death and Inevitable demise’ (above) the early provision of sensitive palliative care is ethically justified and in accordance with principles of good medical practice ...”

37. Mr Hallin’s essential submission, however, was that the case falls into the second category, *Limited quality of life: where there is no overall qualitative benefit*. In his oral submissions, he put it this way, referring to section (A) under the heading *Burdens of treatments*:

“Dr W has described how the very invasive treatments that she would propose to withhold themselves would cause Jake pain and distress. Directly reading from the guidance:

“If a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease.”

So that is a direct analogy with our case.”

38. His alternative submission proceeded as follows:

“The very sad circumstance of this case is that, with seizures which cannot be medicated, we have a deteriorating situation where Jake’s breathing is becoming worse and worse as time passes. The concern, of course, is that he will tip over into the condition of requiring invasive ventilation in order to survive. At that stage the burden of his underlying condition will feed into a burden of treatment as well, and overall his situation would, in our submission, be intolerable.

... So, with a serious deterioration in Jake’s condition that would tip him over the balance into requiring, in order to survive any length of time, invasive or non-invasive ventilation or CPR. But those are circumstances where the Trust’s clear view is that it would not be in his best interests because his

underlying condition and the burden of those treatments would render it intolerable for him.”

39. At that point, he submitted, the situation would fall within section (B) under the heading *Burdens of illness and/or underlying condition*:

“Here the severity and impact of the child’s underlying condition is in itself sufficient to produce such pain and distress as to overcome the potential or actual overall benefits in sustaining life. Some children have such severe degrees of illness associated with pain, discomfort and distress that life is judged by them (or on their behalf if they are unable to express their wishes and views) to be intolerable. All appropriate measures to treat and relieve the child’s pain and distress should be taken. If, despite these measures, it is genuinely believed that there is no overall benefit in continued life, further LST should not be provided, for example, in advanced treatment-resistant malignancy.”

40. I queried with Mr Hallin whether that really described Jake’s case, suggesting that section (B) was focusing very much on the nature of the underlying condition and postulating a case where the pain, discomfort and distress of that underlying condition was such as to be judged intolerable. I queried whether that was so in Jake’s case, because most of the focus of Dr W’s views was on the downside of certain invasive procedures. Although her prognosis as to the long term was gloomy, there was, I suggested, not much material suggesting that, of itself, Jake’s existing condition involved such pain, discomfort and distress as to be intolerable.

41. Mr Hallin accepted this, acknowledging that, at this point in time, the emphasis was certainly towards the burdens of these invasive treatments should they be required in order to sustain life. He added:

“His condition at the moment is not pleasant, in the sense that he has uncontrollable seizures, but it would be wrong to say, as your Lordship points out, that pain, discomfort and distress caused by his present condition would, properly considered of itself, mean that his continued life is intolerable.”

42. Subject to this one, important, qualification, I agree with Mr Hallin’s analysis, accepted as it is by all the other advocates. It reflects the medical evidence and accords with the Royal College’s guidance. In my judgment, both the relevant *legal* principles which I must apply and the Royal College’s *medical* guidance point, as one would expect, in the same direction and, in the circumstances with which I am here confronted, indicate that I should make the order sought. I am satisfied that this is what Jake’s best interests demand.

The order

43. The order I made was in the terms set out in an Annex. Given what I have already said, there is only one aspect of the order which requires any elaboration. Paragraph 6

of the order ends with the words “even though such medications ... in an end of life situation might therefore shorten his life.” I repeat what I said during the hearing:

“I have no doubt at all that, as a matter of law, ... the final two lines of paragraph 6 are entirely proper. It is clear, as matter of law, that if the primary purpose is to relieve distress, the fact that, as a side effect, medication may have the effect of shortening life does not in any way prevent the treatment being lawful.

... the law on this is very clear. It starts off with the famous direction to the jury by Devlin J in *Bodkin Adams* and it has been taken up in a number of subsequent authorities: that, if the primary purpose, as here, is to treat properly and to reduce pain, the incidental consequence of shortening of life is perfectly acceptable, medically, ethically and legally.”

Some final observations

44. Before parting from this desperately sad case there are three points that I wish to emphasise. I can take them conveniently from the transcript of the hearing on 29 May 2015. The first is this:

“the fact that, sadly, both the father and, to a greater extent, the mother have their own difficulties is absolutely no reason at all why their views, their wishes, their feelings should not be taken fully into account by everybody involved in the process, whether treating clinicians or lawyers. Of course they have been fully involved in the process throughout, very properly, by the treating clinicians. [I emphasise] the point that the fact that the parents may lack capacity does not in any way ... reduce the importance of listening to – whether it is the lawyers listening to or the doctors listening to – the views of the parents.

The fact is, on the fundamentals, these parents, faced with this dreadful situation, very much understand the fundamental dilemmas and the fundamental problems. In relation to the fundamentals, they are, so far as I am aware, in just as good a position as any other parent to have views and to express those views. I would be very concerned if the thought ... got about that somehow one pays less attention in these terrible and tragic circumstances to the views, wishes and feelings of parents just because they may have limitations than one would to other parents.”

45. That leads on to the second point:

“the demonstration that [the parents] may not be able to assess and evaluate all the hypotheticals on a range of possible future scenarios has got to be taken within sensible bounds. One asks,

rhetorically, how many parents in this situation would actually be able to grapple with these profound issues which are, in part, tied up with very profound medical issues.”

46. The third point is this:

“forgive me, I cannot remember, but I think it was the father, but forgive me if I have got it wrong and it was the mother, in effect said at one point that he could not come to a decision. That, if I may say so, is a very human and very understandable feeling for him to have. It has got nothing to do with his capacity. It is simply a reflection of the tragic situation in which he finds himself as a parent. There are, I suspect, many parents in this situation who, even if they did not have the difficulties which the father has, would find themselves in exactly the same situation. Indeed those of us who have been involved in these cases for as long as some of us have been will be familiar, from memory or anecdote, of many cases where parents facing these tragic circumstances in effect say “We cannot bring ourselves to decide. We want to leave it to others.”

That, I think, both generally and in the present case, is simply a reflection of the human condition. It is not, as I see it, a reflection of any particular problems or difficulties the father may have. So I think it is very important that there is written into the order so that this is not overlooked appropriate wording making clear that the parents are to be consulted whenever possible.”

I went on:

“I can well understand why, in desperate circumstances like this, parents do not want to have the agony of having to decide, but that is no reason why they should not be involved, and indeed every reason why they should be involved, in being told what is happening and told what is being proposed and given every opportunity to express their views and their wishes and their feelings.”

47. I added this:

“my heart goes out to any parent in the situation of these parents. The reality is that, even those of us who have spent as long as I have spent, both at the Bar and on the Bench, involved in cases like this, can have but a dim understanding of the reality of what the parents are going through. It is a terrible position for any parent to be in. It is a tragic position, and, as I say, my heart goes out, not only to Jake but also to the parents. I have no doubt at all that all that either the father or the mother want to do is to do the very best for their much beloved son. The tragedy is that, even with all the miracles of modern

medical science, there is distressingly little we can do. If I may say so, they have borne themselves, each of them, with great dignity in immensely distressing circumstances.”

48. Annex – the Order:

“UPON [the] guardian agreeing with the application for the declarations sought

AND UPON the [local authority] indicating that:

(1) It agrees with the recommendation of the Applicant (the Hospital) as detailed in Option A of the report of Dr W dated 21 May 2015;

(2) It considers that it is appropriate that the court makes the decision as to the withholding of serious medical treatment for Jake;

(3) It actively encouraged the Hospital to make the application to the court for a declaration regarding the withholding or not of medical treatment not as an abrogation of its shared parental responsibility but rather as an acknowledgment that it is not appropriate for a local authority to give its consent to such serious medical intervention and also to relieve the parents of some of the burden of having to make such a painful and momentous decision as to their son’s health (regardless of whether or not they have capacity to make such a decision)

AND UPON the [parents] not actively opposing the Order sought

IT IS DECLARED THAT:

1 By reason of his minority and by his significant and deteriorating neurological condition Jake lacks capacity (and will always lack capacity) to consent to or refuse medical treatment.

2 In the event of a serious deterioration in Jake’s medical condition it is lawful and in his best interests for the following medical treatment to be withheld:

- (a) Bag and mask ventilation, save to the extent that it is considered to be clinically appropriate in any given situation;
- (b) Endotracheal intubation;
- (c) Invasive or non-invasive ventilation.

3 In the event of a serious deterioration in Jake's medical condition which leads to a cardiac arrest, it is lawful and in his best interests not to receive cardiac massage and resuscitation drugs including inotropes.

4 In the event of a serious infection, including pneumonia, it is lawful and in Jake's best interests not to undergo blood sampling or to receive intravenous antibiotics unless it is considered that such treatment would help to make him more comfortable and/or distress and pain free.

5 In the event of a significant deterioration in Jake's absorption of enteral nutrition it is lawful to withhold parenteral nutrition.

6 In the event that Jake becomes severely distressed and/or is in pain due to further deterioration of his medical condition, it is lawful and in his best interests for him to receive pain medication (such as Morphine) and/or sedation (such as Midazolam) with the purpose of relieving his suffering and/or distress, even though such medications might reduce his respiratory drive and, if in an end of life situation, might therefore shorten his life.

7 For the avoidance of doubt, the above declarations do not prevent those providing medical treatment to Jake from giving him any medical treatment that they consider to be in his best interests at any particular time.

8 It is in Jake's best interests that [his parents] shall continue to be consulted in respect of any significant medical decision making concerning their son ... unless a medical emergency does not provide sufficient time for such consultation to take place."

49. *Annex – Making decisions to limit treatment*

First, *Limited quantity of life*

"If treatment is unable or unlikely to prolong life significantly, it may not be in the child's best interests to provide it.

A. Brain death

Death occurs when a child has irreversibly lost their capacity for consciousness and their capacity to breathe and maintain their cardiovascular circulation.

A determination of death should be made in accordance with accepted medical standards as set out in the code of practice of the Academy of Medical Royal Colleges.

Death may be diagnosed following cardio respiratory arrest or, in a comatose child, it may be diagnosed following evidence of irreversible cessation of brain stem function. When death is diagnosed following formal confirmation of brain stem death by agreed medical criteria, intensive technological support is no longer appropriate and should be withdrawn, unless organ donation is being considered.

B. Imminent death

Here, despite treatment, the child is physiologically deteriorating. Continuing treatment may delay death but can no longer restore life or health. It is therefore no longer appropriate to provide LST because it is futile and burdensome to do so.

Children in these circumstances would be likely to derive little or no benefit from CPR. The aim should be to provide emotional and psychological support to the child and family and to provide them with privacy and dignity for that last period of the child's life ...

C. Inevitable demise

In some situations death is not imminent (within minutes or hours) but will occur within a matter of days or weeks. It may be possible to extend life by treatment but this may provide little or no overall benefit for the child. In this case, a shift in focus of care from life prolongation per se to palliation is appropriate.

In both 'Imminent death and Inevitable demise' (above) the early provision of sensitive palliative care is ethically justified and in accordance with principles of good medical practice ..."

Next, *Limited quality of life: where there is no overall qualitative benefit*

"Considering quality rather than quantity of life is more problematic because of potential or actual differences in views of the healthcare team and children and families as to what constitutes quality of life and the values that should be applied to define it.

In some children, continuing treatment may prolong life significantly. Yet it may be in their best interests to consider limiting it if there is no overall benefit in prolonging life because of the adverse impact entailed. In entering discussions about treatment limitation it is important to acknowledge the importance of the value that the child and his/her parents place upon their life and their view of its quality for that child, regardless of disability. These discussions may arise in the

context of the burdens imposed by a child's illness and/or the treatments that the child is already receiving or that are proposed, their inability to benefit from treatments, or a combination of all three.

A. Burdens of treatments

Some forms of medical treatments in themselves cause pain and distress, which may be physical, psychological and emotional. If a child's life can only be sustained at the cost of significant pain and distress it may not be in their best interests to receive such treatments, for example, use of invasive ventilation in severe irreversible neuromuscular disease.

It is important that all options to relieve or overcome the negative effects of treatment are explored before proposing that it should be limited. However if such treatment can only be delivered at the expense of compromising the child's consciousness, for example, by deep sedation, its potential benefit may be significantly reduced. Other examples of particularly high impact treatments include ECMO, renal dialysis and, sometimes, intensive chemotherapy.

B. Burdens of illness and/or underlying condition

Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome the potential or actual overall benefits in sustaining life. Some children have such severe degrees of illness associated with pain, discomfort and distress that life is judged by them (or on their behalf if they are unable to express their wishes and views) to be intolerable. All appropriate measures to treat and relieve the child's pain and distress should be taken. If, despite these measures, it is genuinely believed that there is no overall benefit in continued life, further LST should not be provided, for example, in advanced treatment-resistant malignancy, severe epidermolysis bullosa.

C. Lack of ability to derive benefit

In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals

and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation.

Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress.”