Case No: B4/2016/2671

Neutral Citation Number: [2016] EWCA Civ 759
IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM THE HIGH COURT OF JUSTICE
FAMILY DIVISION
Mrs Justice Parker
FD16P00264

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 13/07/2016

Before :

LORD JUSTICE McFARLANE
and
LADY JUSTICE KING

- -

Re: A (A Child)

- -
- -

Ms Katharine Scott (instructed by **Bindmans LLP**) for the **Appellant**
Miss Fiona Paterson (instructed by **CAFCASS Legal Services**) for the **1st Respondent**
Mr Michael Mylonas QC and Mr Mungo Wenban-Smith (instructed by **Hempsons Solicitors**) for the **2nd Respondent**

The third respondent was neither represented nor appeared in person.
The fourth respondent appeared in person.

Hearing date: 7 July 2016

- -

Judgment

Lady Justice King :

1. This is an appeal against the making of a declaration by Mrs Justice Parker on 20 June 2016 whereby she declared that:-

> "It is lawful and in A's best interest to remove his respiratory support by extubating him and, if he becomes unstable, not to reintroduce his respiratory support again but instead generally to furnish such treatment by way of pain relief or sedation and nursing as may be appropriate to ensure that A suffers the least distress and pain at the time and in the manner of his dying."

2. The effect of the declaration, if upheld, would be that the ventilator which keeps A, (a little boy born on 16 October 2013 (2 yrs 8 mths)) alive, would be removed and he would die quickly thereafter.

3. The appellant, (the mother) appeals the making of the declaration and accompanying orders on three grounds:

> A. The judge was plainly wrong to make a finding of fact that A was in pain and/or felt pain, and/or misunderstood the evidence in respect of pain, leading to a plainly wrong finding.
>
> B. Failing to carry out a proper, detailed and careful balancing exercise in respect of whether continued treatment was in A's best interests and by failing to do so, erroneously carried out the best interests analysis.
>
> C. Failed to properly have regard to the obligation to protect life.

4. The St George's University NHS Foundation Trust (the NHS Trust) who make the application, and A's CAFCASS children's guardian, each support the judge's decision and say that the challenge to it by the mother is predicated on a wholly understandable, but nevertheless mistaken, premise both as to A's condition and his likely prognosis.

The Facts

5. On 16 November 2015 the mother was driving with A and his baby brother to collect their older brother and sister from school. There was a road traffic accident. An ambulance crew were at the scene of the crash within minutes, but even so A experienced an asystolic period of 17 minutes. Only the fact that the ambulance crew got to A so quickly prevented his death at the scene of the accident; as it was A suffered grave injuries and his parents were warned that he was unlikely to survive. A spinal cord injury seen on an early CT scan was catastrophic. There was in addition a devastating hypoxic brain injury.

6. A is tetraplegic. It is common ground that he cannot feel anything below the neck. A cannot see and, whilst the circuit of his hearing is intact, due to the severity of his brain injury, he is unable to process this into functional hearing. He does not respond to any command, noise or sight. He does not demonstrate any sign of awareness of his surroundings and is minimally conscious. He has no spontaneous respiratory effort, no limb movement, no response to painful stimuli, no cough reflex and weak gag responses. The mother, unsurprisingly, cannot accept the medical evidence as to A's current level of responsiveness. She believes he responds to music, that when he curls his hands it is a sign of pleasure rather than a reflex movement and that there may be some functional vision. She feels he responds to her voice. All the doctors say that the mother is mistaken in her belief.

7. A has remained in paediatric intensive care since the day of the accident and receives 24 hour one to one nursing care. His life expectancy is uncertain but limited.

8. To date A has suffered three episodes of ventilator associated pneumonia and has had multiple urinary tract infections. It is common ground that he will have repeated episodes of pneumonia and at some stage, his treating physician Dr Manna says, the pneumonia will be so severe that he will not be able to be ventilated and will die.

9. The court had before it a raft of expert medical evidence, in particular:-

> "Dr Soumendu Manna, consultant paediatric intensivist, A's treating clinician;
>
> Dr Neil Thomas, consultant paediatric neurologist, from Southampton, who was asked to prepare an independent report by the NHS trust;
>
> Dr Martin Smith, consultant paediatric neurologist at the John Radcliffe Hospital, who was the jointly instructed expert in these proceedings."

10. A's condition is not fixed. Evidence was before the court about his present and future condition derived from a number of sources, in particular (i) what is revealed on scans of his brain, (ii) his clinical presentation including EEGs and (iii) in relation to any future improvement consequent upon his brain 'settling' following the insult it received in the accident. This final element is the only aspect in respect of which there was some degree of disagreement between the experts and is dealt with at paragraph 26 below.

11. Dr Smith explained in his report, and again in evidence, that brain scans carried out on A on 17 November 2015 and 24 February 2016 reveal evidence of widespread and increasing cerebral atrophy; his expectation would be that if a further scan was performed now, it would show further progression of brain atrophy.

12. In addition to the deterioration seen on the MRI scans, Dr Martin Gray, the clinical lead at the NHS Trust, filed a statement dated 16 June 2016 updating the clinical position and detailing concerning developments over the last few weeks. A has started having new episodes of acute onset tachycardia with sweating and pyrexia. Tests for infection (which might have provided an explanation for the pyrexia) have

proved negative. A has, in addition, had episodes of very low heart rate, which demonstrate an autonomic instability which requires close monitoring in intensive care and may get worse over time. On 2 June an EEG was performed, it was highly abnormal and confirmed the findings of severe brain dysfunction. The electrical activities in the brain were suggestive of frequent seizures with a pattern of brainwaves known as "burst suppression pattern". Dr Smith, when asked in evidence about the EEG, said that it "may be one of the worst EEGs I have come across at this distance from an injury". He explained that "burst suppression" is "pretty much, other than entirely flat, the worst appearance brain waves can possibly show", and "the fact that it looks like that seven months after the accident, I have to say, is unfortunately extremely ominous".

13. Given the extent of A's injuries and his poor prognosis, Dr Manna and his team have, at intervals since November 2015, discussed with the family the possibility of the withdrawal of life sustaining treatment. A's father agreed to the withdrawal of A's life support because he felt that A was suffering from intensive care intervention. A's mother understandably did not, and does not, agree to the proposed course of action and wishes the continuation of full intensive care.

14. It was against this backdrop that the NHS Trust made their application.

15. A's paternal grandmother is a party and attended at the hearing below where she was neutral as to her position. She attended court again to hear the appeal. She spoke with quiet dignity and asked that if there was any hope that A would recover, the court would "give him a chance". She spoke of A as being a "treasured child" and of how "just the thought" of losing him was devastating to all the family.

16. The mother has filed a statement and gave evidence before the judge; she was also present throughout the appeal hearing. The mother visits A every day and sits with him for hours at a time, she cannot accept that that there will be no substantial change in A's condition. Whilst the mother accepts the fact that A has a severe brain injury and that he requires ventilation, it is her genuine belief that he is, to a limited degree, responsive to her touch and relaxes when music is played. She is understandably unable to accept the evidence of the treating physicians that what she sees is reflex movement and that the reality is that in his minimally conscious state, A is unaware of his surroundings. Dr Smith saw no response from A to his mother when he visited the hospital in order to prepare his report.

17. When the matter came to trial the doctors who were called to give evidence, namely Dr Manna, Dr Thomas and Dr Smith, together with the children's guardian, were each of the view that A's best interests could only be served by discontinuing life sustaining treatment. Just how hard a decision that has been for the treating team was reflected in the evidence of Dr Manna:-

> "This is the first time in my twenty-seven years I'm coming here and it is prolonging a suffering and we are here. It was not an easy decision for the whole team to come here. I mean, we thought long and hard. It is not only the 8 paediatric intensive consultants, it is 80-100 odd nurses, it is the neurology team, the neurosurgery team, it is the physiotherapists. Everything together, we decided that it is not in A's best interest to

> continue this type of intensive care to keep him alive. He is not benefiting from any of this and that is why we're here, so that deferring it, and for us, we think that it is inhuman to keep A suffering like that. That's why we're here."

18. A has, as has already been noted, been in paediatric intensive care since the date of his accident some 8 months ago. In the event that the declarations are not made, it would be highly desirable for him to be moved to a neuro-rehabilitation unit for long-term care. This in itself would require surgery to allow A to be ventilated through a tracheostomy tube as endotracheal intubation connected to a mechanical ventilator, which is his current form of ventilation, cannot be used outside an intensive care unit. In addition, a gastrostomy peg would have to be inserted to allow A to be fed directly into his stomach. The medical team at St George's, whilst setting out the procedures which would be necessary to facilitate such a move, have made it clear that they consider such invasive procedures to be wholly contrary to A's best interests. In the event, given A's clinical presentation in the last few weeks, it would seem that any attempt to transfer him to a rehabilitation unit is out of the question. Dr Smith also doubted that a rehabilitation centre would currently accept A as a patient.

19. The focus of the oral evidence can be crudely summarised as 'pain' and 'improvement'. Ms Scott, to whom we are grateful for appearing at short notice in the absence of Mr McKendrick QC submits that (i) A is not in pain and (ii) that there will be an improvement in A's level of awareness in the coming months, the full extent of which remains unclear. Her central submission is that in the absence of the burden of pain to A and the benefit to him of some future improvement mean that, had the judge thereafter given proper weight to the sanctity of life, she would have concluded that the application made by the NHS Trust is, at the very least, premature and would have dismissed the application.

20. This core submission links in with the grounds of appeal to the effect that the judge had been wrong to find that A suffers some degree of pain/discomfort and that in conducting the balancing exercise she had erred in giving insufficient weight to the benefit to A of the improvements identified by Dr Smith in the form of increased awareness. As a consequence of these two errors she submits, the judge gave inadequate weight to the obligation to protect life.

Pain

21. The hearing before this court has focused, by reference to detailed consideration of the transcripts of evidence, on what each of the expert witnesses has said about A's ability to feel pain and discomfort.

22. All the evidence is clear that A does not suffer pain below the cortical injury. The issue is as to the interpretation to be put upon observed responses from A when, as happens frequently, secretions have to be suctioned from A's throat above the cortical injury. Dr Manna does not interpret what are referred to as 'grimaces', and the other clinical signs which go with them and are observed when suctioning takes place, as a reflex reaction as opposed to pain. In evidence he said "grimacing, tachycardia, increased heart rate, increased blood pressure and, when happening with the particular procedure, is more likely to be pain and discomfort".

23. Another example of seeming discomfort was noted by Dr Smith when he examined A on 20 May 2016 for the purpose of preparing his report. On that occasion, the ventilator tube was taken out for a few moments in order for Dr Smith to assess A's ability to breathe unaided. Dr Smith described A as having appeared "visibly distressed" for reasons that "are not immediately obvious".

24. Dr Thomas, like Dr Manna, was of the view that even if A did not experience pain on suctioning, he would still experience an unpleasant sensation. Dr Smith however was of the view that, whilst some sensation receptors in the skin are intact above the transection of the spinal cord (roughly from the neck upwards) and that this sensation can therefore get into the brain, the brain itself cannot thereafter make any sense of it due to the severity of the brain injury. In Dr Smith's view Dr Manna was identifying signs of distress as if in someone who is aware, but, in his opinion, A is unaware and therefore not in distress. Dr Smith suggested that an instinctive drowning reflex might be an explanation for the "distress" exhibited by A when he, Dr Smith, had removed his ventilator tube.

25. The judge carefully summarised the views of the experts in relation to each's view on A's ability to feel pain. She also considered evidence given by Dr Manna that when A is physically manipulated there is physical agitation demonstrated by a raised heartbeat. The judge did not accept Dr Smith's view that A did not suffer because his brain does not function. She said at paragraph 28:-

> "I cannot find precisely what causes a pain/discomfort/sensation but I am satisfied that hospital procedures which relate to the neck area, particularly suctioning, are painful or at least very unpleasant for him. This is a procedure which has to be carried out on a frequent number of occasions and will have to continue to be carried out if a tracheotomy was performed and an airway inserted."

Improvement

26. Dr Smith explained during the course of his evidence, that A's brain has suffered a severe insult leading to encephalopathy. By way of illustration he said that if one thinks of a child's 'snow storm' dome, which has been shaken up, it takes a long time for the snow to settle; in the same way, he said, it can take the brain months to settle following an injury. Dr Smith's view is that whilst A's brain will always be poorly functioning as a consequence of the devastating injury, as organisation of the brainwaves occurs over time there can be some modest improvement in A's level of awareness. The type of improvement Dr Smith envisaged was a less than a 1% chance that he would be able to blink to communicate, but that if he developed some limited awareness of his surroundings he may well draw comfort from the touch of someone. He might demonstrate some sign of pleasure in having his head massaged and whilst it was "possible but unlikely" that he would smile, it was somewhat more than the 1% chance related to blinking, possibly up to 20-30%. Dr Smith agreed that "measurable objective gains could be achieved over the next 18 months". Even if there is some modest change however A will not recognise his mother, or that music is music, or to whom the soothing voice belongs.

27. Dr Smith described the potential improvements as 'modest' and having set out the form they could take said:-

> "I think I have described a pattern which is not without some comfort but is, by most standards of expectations of what we would wish for for our children, is bleak."

28. Dr Smith expressed his concern that, as a consequence of some modest increased awareness on A's part, he would become more aware of the burden of his illness and of the burden of the many and intrusive treatments to which he is subject in order to keep him alive. Dr Smith said this:-

> "In the triad of ways to assess a child, the clinical examination, the MRI brain scans, and the evidence of function of the brain and the EEG are all lined up as being ominous. The only reason I'm entertaining the possibility of any improvement at all is that experience has taught me that if you wait long enough there are very few children that don't improve somewhat, but the hard evidence is all ominous."

29. Dr Manna did not agree that there would be any meaningful improvement in A's condition now or in the future.

30. Notwithstanding his evidence of the possibility of the sort of improvement he described, Dr Smith, in common with the other experts, was clear that the decision as to whether to withdraw lifesaving treatment should be made now because he could foresee that time would 'buy' a greater burden of suffering than it would 'buy' benefits. Dr Smith, again in common with all the doctors, has expressed sympathy for the unimaginable position this mother finds herself in but, when pressed, he said that his anxiety from his professional experience was that "buying time for the mother's benefit will almost certainly allow a greater degree of suffering". As the judge said at paragraph 48:-

> "Dr Smith's final advice to me from the witness box is that he maintains his view expressed in his report that, whatever the potential for the modest improvements which he described, his advice was still that treatment should now be withdrawn in order that A's suffering would not intensify. This leads me to conclude that notwithstanding Dr Smith's evidence, which looked at accentuating the positives rather than the negatives, the possibilities of positive improvements rather than the static or deteriorating state, he does perceive there to be suffering in A's life."

The law

31. Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental

Capacity Act 2005. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 22:-

> "Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it."

And from 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 towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."

32. Having indicated that, on the facts of *Aintree*, whilst she herself may have come to a slightly different conclusion in relation to one form of the proposed treatment, Baroness Hale nevertheless said at para 42:-

> "But if the judge has correctly directed himself as to the law, as in my view this judge did, an appellate court can only interfere with his decision if satisfied that it was wrong: *Re: B (A Child)* (Care Proceedings: Appeal) [2013] UKSC 33; [2013] 1WLR 1911. In a case as sensitive and difficult as this, whichever way the judge's decision goes, an appellant court should very slow to conclude that he was wrong."

33. The judge in her judgment set out the well-known and helpful analysis of the proper approach to the balancing exercise found in Holman J's judgment in *Re: NHS Trust v MB and Others* [2006] EWHC 507 (Fam); [2006] 2 FLR 319. In her judgment the judge at paragraph 42 highlighted the following factors from *MB*:

> "1. The decision must be objective; not what the judge might make for him or herself, for themselves or a child;"
>
> 2. Best interest considerations cannot be mathematically weighed and include all considerations, which include (non-

> exhaustively), medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations;
>
> 3. There is considerable weight or a strong presumption for the prolongation of life but it is not absolute;
>
> 4. He quoted Lord Donaldson of Lymington in *Re: J (A Minor)* (Wardship Medical Treatment) [1991] FAM 33 at page 46, that there is a strong presumption in favour of prolonging life but account must be taken of the pain and suffering and quality of life, and the pain and suffering involved in proposed treatment against a recognition that even very severely handicapped people find a quality of life rewarding.
>
> 5. Cases are all fact specific".

34. Although she did not set it out in the judgment, the judge went on to say that she paid considerable regard also to paragraph (x) of Holman J's list of factors to be considered. Against the backdrop of the strength of her views and the unstinting devotion of this mother paragraph (x) is worthy of rehearsing:-

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

35. In the context of the submission made that the modest improvements which may come about in the coming months as a consequence of the "snow storm" effect, Ms Scott has referred the court to *In Re: M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2012] 1 WLR 1653. Ms Scott relies on this case on the basis that, whilst Baker J was dealing with the future of an adult, that patient, like A, was in a minimally conscious state. Whilst Ms Scott properly accepts that the present case is very different, the court should, she submits, bear in mind para 259 of the judge's judgment in *Re M*, where he emphasises that:-

> "It is therefore of the utmost importance that every step should be taken to diagnose the patient's true condition before any application is made to the court".

36. Similarly she draws the court's attention to *St George's Healthcare NHS Trust v P and Q* [2015] EWCOP 42, which is again a case involving a minimally conscious

adult, and again a case with a significantly different factual matrix from the present case. However Ms Scott relies on it to the extent that she draws the court's attention to para 46 where Mr Justice Newton says:-

> "The Court of Protection is cautious when considering whether to permit cessation of life sustaining treatment, where the diagnosis is unclear and particularly when the protected party is in a minimally conscious state with real or uncertain prospects of recovery that caution is all the greater having regard to the sanctity of life."

37. Put simply, Ms Scott's case in reliance on these authorities and her interpretation of Dr Smith's evidence about "improvements" is that A's medical condition has not yet plateaued, that there will be changes and that the application is therefore premature. Ms Scott says therefore that per para 46 of *Q* there are "real or uncertain prospects of recovery" although she accepts that there is no doubt about the essential diagnosis in A's case.

38. Finally in relation to the law, Ms Scott reminds the court that improvement or quality of life is a spectrum and should not be judged in terms of absolutes. In particular she refers again to Baroness Hale in *Aintree* where she says at paragraph 44:-

> ". . . But where a patient is suffering from an incurable illness, disease or disability, it is not very helpful to talk of recovering a state of "good health". The patient's life may still be very well worth living. Resuming a quality of life which the patient would regard as worthwhile is more readily applicable, particularly in the case of a patient with permanent disabilities."

39. Ms Scott's submission is that the improvements identified by Dr Smith, if accepted at their highest (and it must follow, ignoring the deterioration seen on the MRIs, EEGs and clinically), amount to measurable benefits which would drive a court to conclude that those improvements would lead to A "resuming a quality of life which [A] would regard as worthwhile".

Royal College Guidance

40. The President of the Royal College of Paediatrics and Child Health has issued from time to time guidance entitled "Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children; a Framework for Practice" (the Guidance). This guidance was updated in March 2015 and is, as it is described in the foreword, "A live document and not an end point for discussion and learning". The Guidance is exactly that. It is not binding on a court and has no legal force. Nevertheless, in reality it forms the backdrop against which multidisciplinary medical teams conduct their assessments when they address what is described in the Guidance as "the complexity, challenge and pain of that most difficult of decisions: is the treatment we are providing no longer in the best interests of the child". Each of the experts has used the Guidance in this case. The Guidance sets out three sets of circumstances where treatment limitation can be considered where it is no longer in the child's best interests for it to continue, because the treatment cannot provide overall benefits. The three categories are:-

1) When life is limited in quantity;

2) When life is limited in quality;

3) Informed competent refusal of treatment.

41. The second of those categories, namely 'when life is limited in quality' is that which the experts and Children's Guardian believe applies in A's case. Each category is thereafter divided into three sub-categories. So far as the 'quality of life' category is concerned it provides:

> "When Life is Limited in Quality
>
> This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatments itself. These comprise:
>
> A. Burdens of treatments where the treatments themselves produce significant pain and suffering so as to outweigh any potential actual benefits;
>
> B. Burdens of the child's 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 any potential or actual benefits in sustaining life.
>
> C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life."

42. The medical experts have regarded this as a case which falls into the third of those sub-categories, namely "Lack of ability to benefit", although it should be remembered that Dr Smith's oral evidence was that in the event that (as a consequence of the amelioration of the snow storm effect on A's brain) there is some limited increasing awareness in A, that would lead to him feeling that category 'A. Burdens of treatments' would also become engaged.

The Grounds of Appeal

43. Ms Scott's first ground of appeal is that the judge was plainly wrong to make a finding of fact that A was in pain and/or felt pain and/or she misunderstood the evidence in respect of pain leading to a plainly wrong finding.

44. Ms Scott carefully took the court through the transcripts of evidence highlighting, with precision, the references to pain. She then took the court to those passages of the judgment which were, she said, inconsistent or contrary to the evidence. Mr Mylonas QC, on behalf of the NHS Trust, responded by producing a table setting out the oral evidence given by the doctors, supporting the judge's finding that A is capable of suffering from pain or discomfort.

45. The area of medical disagreement in relation to pain is clear. Dr Manna, Dr Thomas and their team oversee the suctioning of secretions from A's airways and mouth. Suctioning can take place every few minutes in the event that A is currently suffering an infection or every few hours in the event that he is not. What is observed by those caring for A is that on a significant number of occasions suctioning provokes grimacing, gasping, raised blood pressure, raised heartbeat and sweating. A similar response was noted by Dr Smith when he briefly removed A's ventilation tube as referred to in paragraph 24 above.

46. Dr Manna's evidence was that, whilst he deferred to the neurologists, his view was that A's response is not like other people who have an intact brain, he did not believe that what was observed was reflex action but more likely to be as the result of pain or discomfort. Dr Thomas, like Dr Smith, is a neurologist. His view was that, whilst A does not feel deep suction, which would be below the line of his spinal injury, suction to the oropharynx is a different matter as A retains innovation at that level.

47. Where Dr Smith differs is that whilst Drs Manna and Thomas believe that although the brain injury means that A cannot respond in the same way as he would do otherwise, nevertheless the physical manifestations observed by the treating team are classic responses to pain or discomfort. For his part Dr Smith is of the view that, as those parts of the brain that process pain are demonstrably injured on an MRI scan and demonstrably not working on an EEG, then the only conclusion a neurologist can make is that pain is not felt. Dr Smith therefore disagrees with his fellow neurologist Dr Thomas and with Dr Manna as he believes that A does not feel pain and is therefore not in distress.

48. It may well be that Dr Smith himself hit the nail on the head when, in the context of disagreeing with Dr Thomas' view that intubation requiring suction is <u>in itself</u> uncomfortable and sometimes painful, he said "Dr Thomas is a highly respected colleague but I think that this is one of these instances where, with a reasonable range of professional opinion, my perception is that the act of suctioning is not desperately distressing".

49. That being so, the judge, having seen and heard the evidence had to resolve this difficult issue and in doing so had to choose between what was (given the level of expertise and experience of the experts before her) undoubtedly a 'reasonable range of professional opinion'.

50. Ms Scott is critical of the judge's judgment and her analysis of the evidence in relation to A's continuing ability to feel pain and or discomfort. Whilst almost any judgment, analysed line by line by an advocate as skilful as Ms Scott, can be open to criticism, in my judgment, given what Dr Smith himself recognised as the potential for a reasonable range of professional opinion as between the neurologists in this case, taken together with the observations of the clinical treating physicians, nurses and physiotherapists over many months, it cannot be said that the judge was plainly wrong in preferring the interpretation of Drs Manna and Thomas that the physical signs which they had observed, and which are the commonplace signs associated with pain and/or discomfort, are evidence of precisely that.

51. In reaching this conclusion I have had in mind the fact that Dr Thomas, during the course of his evidence, somewhat strayed into anecdote. I also have in mind that the

judge, having carefully set out the burden of proof in paragraph 33 of her judgment then said at para 35:-

> "On all the evidence, particularly the careful clinical observations of which I have strong evidence from the hospital, I accept that A does suffer pain above neck level. It has certainly not been disproved that he suffers pain there."

That seeming error must be considered in the light of her analysis overall and the balance of the paragraph where the judge went on to say:-

> "No-one has been able to answer the question, why do you need a fully functioning brain in order to experience pain? Dr Smith accepted in evidence that lower organisms, down to quite simple organisms which do not have fully developed brains in the way that we as human beings do, suffer pain – it is a very basic and primitive response."

52. In my judgment, when read as a whole, the judge had not in fact reversed the burden of proof and the appeal cannot succeed on the basis that the judge had been plainly wrong in her finding that A suffers from pain and or discomfort.

53. The second ground of appeal relates to the judge's balancing exercise in respect of whether continued treatment was in A's best interests. Ms Scott seeks to build on her assertion that A does not suffer from pain or distress in support of this ground. She says that the judge erred in failing adequately to put into the balance the fact that A's life is not burdensome as he is not in pain. That important factor having been removed from inclusion in any balance sheet, as a disadvantage of continued treatment, the judge, Ms Scott says, then failed to include on the opposite side, the benefit to be gained to A from the modest improvement that might be seen in the months ahead. In that context, Ms Scott says, the court must bear in mind that one is not looking at recovery as being the appropriate yardstick. In any event, she says, the fact that the extent of any improvement remains unclear means that the whole of the balancing exercise is undermined as having been premature. Ms Scott accepts that the judge undertook a balancing exercise, but her attempts to do so were fatally flawed, she says, by her failure to give proper weight to the absence of burden as a consequence of A suffering no pain and the expectant benefit of increased awareness in the future.

54. This analysis in turn feeds into ground 3 which is the suggestion that the judge failed to have regard to the obligation to protect life. Ms Scott submitted that had the judge given proper weight to the sanctity of life she would have accepted that the application was premature and refused to make the declarations.

55. As acknowledged by Ms Scott, the judge had carried out a careful balancing exercise. She took into account her findings in relation to pain, that she was unable to accept the mothers' perception of A's functioning and she specifically considered whether or not the application was premature. But with respect to Ms Scott, the whole premise of her appeal rests on her interpretation of Dr Smith's evidence in relation to 'pain' and 'improvements' and of those findings as being determinative of the outcome. To approach the case in this way not only ignores the evidence in relation to A's

progressive brain atrophy and the 'ominous' EEGs, but also fails to acknowledge or properly to take into account the fact that Dr Smith supports the application. One cannot look at Dr Smith's evidence in relation to 'pain' and 'improvement' without also taking into consideration:-

i) that his conclusion that life supporting treatment should be withdrawn rests on category 2C of the Guidance namely A's 'Lack of ability to benefit' in that the severity of A's condition is such that it is difficult or impossible for him to derive benefit from continued life. Dr Smith reached that conclusion notwithstanding his view is that A is <u>not</u> suffering pain or discomfort and that A's case does not therefore currently fit within 2A of the Guidance, namely the 'Burden of treatments'.

ii) that any modest improvement brought about by the amelioration of the 'snow storm' effect, far from being perceived as a benefit by Dr Smith, would lead him to think that the case would shift from being one falling only within the 'benefit' category to one which would also fall within the 'burden' category and as such reinforces his view that treatment should be withdrawn.

iii) Dr Smith's recommendation was that the decision should be made now because he could see that time would buy only a greater burden of suffering than it would buy benefit. His evidence was that "buying time for the mother's benefit would almost certainly allow a greater degree of suffering."

Discussion

56. In her judgment the judge referred to a detailed balance sheet helpfully prepared by Mr Ford, who represented Ms Julian, A's CAFCASS guardian. I am well aware of their value and that the use of such balance sheets is routine in multidisciplinary meetings against the backdrop of the Guidance. Recently in *F (A Child) (International Relocation Cases)* [2015] EWCA Civ 882, Lord Justice Ryder endorsed their use in child welfare assessments. In his supporting judgment in *Re F,* Lord Justice McFarlane however expressed caution at [52]:-

> "Whilst I entirely agree that some form of balance sheet may be of assistance to judges, its use should be no more than an aide memoire of the key factors and how they match up against each other. If a balance sheet is used it should be a route to judgment and not a substitution for the judgment itself. A key step in any welfare evaluation is the attribution of weight, or lack of it, to each of the relevant considerations. One danger that may arise from setting out all the relevant factors in tabular format, is that attribution of weight may be lost, with all elements of the table having equal value as in a map without contours."

57. I would respectfully endorse those views. The courts have long recognised that in disputes in respect of serious medical treatment the matter should be brought before

the court. See for example *NHS Trust v SR Radiology and Chemotherapy* [2013] 1 FLR 1297. At the end of the day, as was emphasised by Baroness Hale in the *Aintree* case, the test to be applied by the courts in such cases is simply this: what is in the best interests of the child at the particular time in question, having regard to his welfare in the widest sense, not just medical, but social and psychological? Too heavy a focus on a balance sheet may, as was recognised by McFarlane LJ, lead to a loss of attribution of weight. In the present case almost the entirety of the oral evidence and a substantial part of the judgment related to the issue of 'pain'. Although it is undoubtedly the case that a single factor can be of such overwhelming importance as to be determinative (for example where a child is in significant and unmanageable pain or distress) the emphasis here focused disproportionately on one item which, although relevant, did not in reality go to the heart of the decision. As a consequence there was a real danger, repeated again before us, of a failure to stand back and consider A's welfare in its widest sense. The guardian was not so distracted, saying in her report:-

> "51. Sadly A's life has now changed for ever and the future painted for him is very bleak. He has severe brain damage. He cannot speak or see. He does not respond to command or noise. He is fed by a tube. He will always be completely paralysed in all four limbs. He is totally dependent on a machine to breathe and this will never change. Whatever happens, A will sadly always be dependent on a very high level of care, with an inability to communicate with those around him.
>
> 52.. . .
>
> 53. The medical consensus is that continued ventilation is not in A's best interest and it is with a very heart that I have to agree. From all the information available to me I do not see how it can be in his best interests to have to endure the life that he currently leads absent of any quality and plagued only with the burden of the illness and procedures that keep him alive."

58. Neither did the judge in her analysis lose sight of the overall picture for this little boy. Her conclusion was as follows:-

> "61. There is every prospect of A's life being prolonged completely against his interests. He is being kept alive through ventilation. Treatment is futile save simply to keep him alive, with a faint prospect, on one opinion only, of a very slight change which will give him no measurable benefit. I do not think that A would want this life for himself.
>
> 62. I see no advantage to him and much detriment in adjourning the decision, for the reasons identified by Dr Smith. I put a higher emphasis on the burdens than Mr Wenban-Smith because of the evidence which I have accepted as to pain and suffering. Even if I am wrong in that assessment, and even if his life were completely pain free, I would come to the

> conclusion that there is no measurable benefit to him to continue in his present condition and it is simply inhumane to permit it to continue. It is not in his best interest to continue treatment other than palliative care, and it is in his best interests for all other treatment to be withdrawn."

59. I would dismiss the challenge to the judge's finding as to A's ability to feel pain and discomfort. Even had I found that ground of appeal to have been made out, in my judgment the judge, having correctly directed herself as to the law and weighed up with care all those factors which would inform her as to A's best interests in the widest sense, could not be said to have been wrong in agreeing with all of the experts and with A's children's guardian that the time has now come to withdraw treatment other than palliative care.

60. For those reasons I would dismiss the appeal.

Lord Justice McFarlane

61. I agree entirely with my lady's judgment. We have given the most anxious consideration to the decision that falls to be made in this tragic case. In particular, I heard the clear and heartfelt message to this court that came from A's grandmother; we have endeavoured to undertake the charge that she gave to us. At the end of the process of evaluating the evidence and the law, it is however clear to me that the only justifiable outcome is for the appeal to be dismissed and for the judge's order to stand.