Neutral Citation Number: [2026] EWHC 348 (Fam)

Case No: FD25P00754

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 19 February 2026

Before :

THE HONOURABLE MR JUSTICE GARRIDO

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Between :

Cardiff and Vale University Local Health Board — **Applicant**

- and –

(1) SR — **Respondents**

(2) RR

(3) TR
(by his Children's Guardian)

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Victoria Butler-Cole KC (instructed by **Cardiff and Vale University Local Health Board**) for the **Applicant**
Janet Bazley KC and **Tahmina Rahman** (instructed by **RWK Goodman LLP**) for the **1st Respondent**
Denise Gilling KC and **Gemma Kelly** (instructed by **Duncan Lewis Solicitors**) for the **2nd Respondent**
Emma Sutton KC and **Lucy Leader** (instructed by **Robertsons Solicitors**) for the **3rd Respondent**

Hearing dates: 12 and 13 February 2026

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Approved Judgment

This judgment was handed down in Court No 47 at 10:00 on 19 February 2026 and was circulated to the parties or their representatives by e-mail.

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THE HONOURABLE MR JUSTICE GARRIDO

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media and legal bloggers, must ensure that this condition is strictly complied with. Failure to do so may be a contempt of court.

Mr Justice Garrido:

1. TR was born to devoted parents who love and cherish their only child. He has a confirmed diagnosis of Leigh syndrome, a congenital mitochondrial disease which is described as severe and progressive, for which there is no treatment and from which I am told he will sadly not recover. Following respiratory arrest in January 2025, he has needed mechanical ventilation, other invasive procedures and intensive care. In April, his condition further deteriorated and subsequent investigations have confirmed extensive, and apparently irreversible, brain damage.

2. The unanimous evidence of medical experts and clinicians, accepted by TR's children's guardian, is that life sustaining treatment is causing him harm (but probably not pain) without any appreciable benefit and is therefore not in his best interests. The applicant proposes alternative treatment in accordance with a palliative care plan. His parents, however, whilst facing with fortitude the bleak prognosis for their son, contend that TR derives sufficient benefit from life sustaining treatment to justify its continuation in the current circumstances. It is a credit both to the parents and the medical staff that despite this disagreement, their relationship has remained amicable and positive to their, and most importantly TR's, benefit.

3. It now falls to me in this judgment to determine which of these two options is in TR's best interests.

4. By the conclusion of a hearing last week, I had received and have regard to the written evidence filed and contained in the court bundle, a schedule of events extracted from over 6000 pages of medical notes and other records, the oral evidence of Dr Majumdar, Professor Playfor, Dr C, mother, father and the children's guardian, and the written and oral submissions of leading and junior counsel.

   LAW

5. The law in this area is well settled and the respondents agree the way in which it is summarised on behalf of the applicant, which I adopt.

6. I have jurisdiction to make a declaration about medical treatment where a child cannot make decisions for himself and there is disagreement between the treating doctors and those with parental responsibility, *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117.

7. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable, *Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33.

8. The test that I am required to apply is simply whether the proposed treatment is in TR's best interests, *Great Ormond Street Hospital for Children NHS Foundation Trust and Yates and others* [2017] EWCA Civ 410; [2018] 1 All ER 569 (CA) @ [112]: "…*the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view*."

9. In *Re A (A Child) (Withdrawal of Medical Treatment)* [2016] EWCA Civ 759; 151 BMLR 39, the Court of Appeal confirmed that the following passage from *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591, a case concerning withdrawal of intensive care from an adult, also applies to cases concerning children:

> *"[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."*

10. Although the welfare checklist in section 1(3) of the Children Act 1989 does not strictly apply to this decision, I am required to conduct an holistic best interests analysis that incorporates the checklist factors, *Fixsler v Manchester University NHS Foundation Trust* [2021] EWCA Civ 1018; [2021] 4 WLR 123 @ [80]. In doing so, the views of a child's parents are not determinative, any more than the views of the treating doctors or the assumed view of the child. Religious beliefs are part of the best interests analysis, but I should be careful about ascribing religious beliefs to a very young child who has a limited understanding of such concepts, *Fixsler* @ [85].

11. The following analysis, taken from *Portsmouth Hospitals NHS Trust v Wyatt and Anor* [2005] EWCA Civ 1181; [2005] 1 WLR 3995 and *An NHS Trust v MB* [2006] EWHC 507 (Fam); [2006] 2 FLR 319, has been repeatedly followed, particularly in the context of decisions concerning young children who cannot express their own opinions about treatment:

> *i) The judge must decide what is in the best interests of the child.*
>
> *ii) In making that decision the welfare of the child is the paramount consideration.*
>
> *iii) The judge must look at the question from the assumed point of view of the child.*

iv) There is a strong presumption in favour of a course of action that will be likely to preserve life but that presumption is not irrebuttable.
v) The term "best interests" encompasses medical, emotional and all other welfare issues.
vi) The court must consider the views of the doctors and parents.
vii) Each case will turn on its own facts.
viii) The court must conduct a balancing exercise in which all relevant factors are weighed. This is not a mathematical exercise but it is an objective one.

12. I should exercise caution when considering the issue of the extent to which a child is experiencing pain. The Court of Appeal noted in *Re A* (above) @ [57] that:

> "*…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*.

13. Whilst applying the caution referred to by MacDonald J in *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2530 (Fam); [2020] 3 All ER 663 @ [175], I am able to have regard to the possibility that a child can feel pain from continuing treatment, even if it is not likely on the application of the civil standard of proof, *Newcastle upon Tyne Hospitals NHS Foundation Trust v H and others* [2022] EWFC 14; 194 BMLR 126 per Hayden J @ [42]: "… *I consider it would be quite wrong, when balancing the difficult and sensitive issues raised here, not to take account of the fact that treatment might be causing H pain."*

14. I note, however, that the Court of Appeal has confirmed that a child can experience physical harm from medical interventions even if they are not conscious and do not experience pain, *Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust & Anor* [2021] EWCA Civ 362 @ [60]-[62], a decision of particular relevance in this case.

15. Finally, I acknowledge that the rights of TR and his parents variously under articles 2, 8 and 9 of the ECHR are all engaged and must be considered. Of significance in this case is the respect to be afforded to the parents' religious views, and those they ascribe to TR, pursuant to article 9.

EVIDENCE

16. I heard first from Dr Anirban Majumdar, consultant paediatric neurologist, instructed by the parties as a single joint expert. He has extensive experience in paediatric neurology, including the treatment of children with mitochondrial conditions, two of whom were diagnosed with Leigh's syndrome.

17. He reported that he is not aware of any treatment for Leigh's syndrome. His assessment of TR has led him to the conclusion that TR is in a persistent vegetative state with no realistic prospect of recovery. TR's profound brain and brain stem disfunction is permanent and irreversible. He considers that TR is unable to perceive external stimuli or the presence of his family, and has no awareness 'whatsoever' of his surroundings. Any movements made by TR are most likely to be reflex in nature. The absence of a gag/cough reflex, loss of any or any meaningful visual function as a result of optic atrophy, sensorineural hearing loss and the absence of a consistent sleep/wake cycle are all illustrative of the profound nature of TR's neurological disfunction.

18. He concludes that children in a persistent vegetative state are generally thought not to have sufficient brain function to perceive pain and suffering. He considered that it required 'nuanced' consideration because when a child is in a persistent vegetative state, he cannot acknowledge painful stimuli because of his low brain function. 'Grimacing' is not necessarily a response to pain and where brain function is so low, may result from any stimulus. Nevertheless, the invasive treatment and intensive care required to keep TR alive constitutes a 'huge' burden.

19. When cross-examined, he repeated that the events in the schedule and observations by mother are not indicative of TR's improvement to any significant degree. Some recordings, such as a nurse noting coughing, were 'idiosyncratic'. He acknowledged that Professor Playfor noted a degree of neurological improvement but described this as a 'tiny drop of water in the ocean of damage' that TR has experienced. He observed that the 'cruelty' of Leigh's syndrome is that some minimal changes can occur leading to false hope.

20. He accepted that Dr C had found pupillary response where he had not, and had also noted reports of TR blinking, and conceded that this may indicate some small degree of awareness. However, recovery requires sustainable, general improvement that TR does not demonstrate. Individual, isolated observations of minimal neurological function must be put in the context of the wider picture. He explained that he had touched TR, moved his arms and legs, pressed his forehead and examined his reflexes, all with no response. His minimal reported response to music therapy, rather than indicating improvement, is another example of profound damage.

21. He acknowledged that there is a fine distinction between a persistent vegetative state and a minimally conscious state. Although an occasional Glasgow coma scale score of 10 is more consistent with the latter, every other parameter and the broad range of evidence leads him to conclude that TR is in the former. He further acknowledged the absence of seizures in TR, noting that they are common but not inevitable. He thought seizures would probably develop as the terminal stage of the illness further develops.

22. Professor Stephen Playfor is a consultant paediatric intensivist, also instructed by the parties as a single joint expert. He has extensive experience of mitochondrial disease, and in his hospital they see one or two children each year with Leigh's syndrome from across the north of England.

23. In his report, Professor Playfor comprehensively reviewed TR's medical history. He described TR as suffering from clinical problems which include severe global neurological failure, inadequate respiratory drive with ventilator dependence, absent cough, gag and swallowing reflexes, no purposeful limb movements and artificial feeding via a jejunostomy tube. He took a comprehensive history from nursing staff, conducted his own examination of TR and spent time talking to TR's mother and grandmother.

24. He observes that TR's neurological status appeared to be at its worst in May/June 2025 and since then, TR has shown a 'modest degree' of neurological improvement. He considers that this 'step-wise' pattern of deterioration with a plateau phase, or even some recovery of neurological function, is typical of Leigh's syndrome. It is his opinion that TR 'does not have any cognitive awareness of the world around him and does not experience pleasure'. He concludes that it is impossible to be certain if TR experiences discomfort or pain, but it is likely that he does not experience pain. He does not believe that there is any prospect of TR regaining cognitive awareness or the ability to breathe independently.

25. The Professor opines that there is no benefit to continuing treatment given the severity of TR's brain injury, from which he will not recover, and the apparent absence of enjoyment of any aspect of life. As for any burdens, they are minimal in terms of pain or discomfort. However, the physiological burdens are significant, and are likely to include pneumonia, worsening respiratory failure, bone disease due to osteopenia (secondary to lack of load-bearing and associated with pathological fractures and the development of renal stones), scoliosis with associated cardio-respiratory impairment, progressive gut failure, increasingly difficult to control seizures, and a risk of infective complications and sepsis. This is despite relatively low ventilator pressure and excellent care resulting in skin, tongue and oral condition all being good.

26. He told me that there is nothing in the reported observations of TR, either in the medical notes or by mother, that make him suspect that TR is conscious of the

environment around him. What is apparently seen in TR by his mother is neither consistent nor indicative of a predictable and complex pattern of response that would be expected if there was any consciousness. Mirroring Dr Majumdar's evidence, the Professor said that 'change is not the same as improvement'. It is necessary to look at the whole scale of TR's responses. What is reported does not take him over the threshold where he experiences the environment around him.

27. When cross-examined, the Professor acknowledged that there has been a change since the lowest point last year, but the long-term, relentless trajectory is downwards. Despite what appears to be a plateau, deterioration is continuing. Leigh's syndrome progresses relentlessly at a cellular level regardless of clinical observations. The documentation of coughing or hiccups does not suggest improvement. There is a clear absence of a repeatable, predictable cough and in any event, it is more likely that what has been recorded is not coughing. Wholly inadequate breathing that cannot be sustained independently is what is described in the notes. Other documented changes are simply that; they do not indicate improvement and are not consistent or repeatable.

28. When asked particularly about the reports of music therapy, he cautioned against allowing the evidence of non-clinical members of the team to take undue prominence. The descriptions that were put to him were 'wildly out of keeping' with medical assessments; some statements are simply 'unsupportable'. Whilst acknowledging the benefits to families in intensive care of music therapy, he said that it is 'not reasonable' to suggest that an interaction with a musical instrument can generate a cognitive response that is otherwise not possible.

29. Dr C is a consultant in paediatric intensive care. He has been responsible, with his clinical colleagues, for the intensive care support provided to TR since his admission on 20 January 2025. Prior to this application being made, he obtained second opinions about TR's presentation from Dr Brierley, consultant paediatric intensivist and Professor Robert McFarland, professor of paediatric mitochondrial medicine.

30. Dr C states that TR's diagnosis of Leigh's syndrome is not in doubt and has been confirmed clinically, radiologically, biochemically and genetically. He describes it as a severe, progressive and fatal neurometabolic disorder by which TR has sustained irreversible brain damage. There is no treatment available to cure or attenuate the severity of TR's condition, which he describes as presenting as follows:
a. Severe global neurological failure,
b. Absent cough and gag reflex,
c. Absent respiratory drive,
d. Ventilator dependence,
e. Absent swallow,
f. No purposeful spontaneous limb movements, intermittently grimaces to suctioning,
g. Fed via a jejunostomy tube due to intolerance of feeds via his gastrostomy.

31. He summarised his own opinion, and that of Dr Brierley and Professor McFarland as follows:

29. In summary, I have concluded that:

a. TR has a fatal, progressive brain disease;
b. He is completely dependent on medical personnel and devices for breathing, nutrition and hydration;
c. I have no objective evidence that he has purposeful interactions with his environment;
d. It is most likely that TR has no conscious experience at all, but if he does, he will be experiencing pain as a result of the medical interventions keeping him alive;
e. No medical intervention is available to improve his condition. His neurological state will continue to worsen.

31. Dr Joe Brierley, Consultant Paediatric Intensivist and Director of Paediatric Bioethics, Great Ormond Street, London:
a. TR's brain injury is irreversible and progressive;
b. TR no longer interacts with the world around him;
c. There is no purposeful movement;
d. There are some spontaneous eye movements but he cannot fix and follow;
e. He is unable to see;
f. He does not react to sounds;
g. The occasional changes in skin pattern are likely due to vasomotor control variation for his badly damaged brain stem/autonomic rather than any interaction with the world;
h. Agreement that TR should not receive a tracheostomy and long-ventilation is not clinically appropriate;
i. Agreement that TR should not be resuscitated if his heart stops, receive inotropic medicine if his circulation worsens or receive renal replacement therapy if his kidneys fail, is appropriate;
j. TR cannot benefit from the treatments he receives;
k. The ongoing treatments that are keeping TR alive include several that are, by their nature, invasive and burdensome specifically invasive mechanical ventilation, frequent endotracheal suctioning and pressure area care.

32. Professor Robert McFarland, Consultant Paediatric Intensivist and Professor of Paediatric Mitochondrial Medicine, Newcastle upon Tyne NHS Foundation Trust:
a. TR has a diagnosis of Leigh syndrome;
b. TR has had catastrophic deterioration that is not reversible;
c. TR is in the terminal phase of his mitochondrial disease;

d. It is very unlikely that TR will develop cardiac or respiratory problems as a direct result of his mitochondrial disease;
e. His brain disease will become worse so that seizures will become more likely;
f. The current situation could continue indefinitely leaving TR, ventilated, able to open his eyes but without meaningful interaction with his environment or those around him including his family.

32. Dr C responded to concerns raised with him on 21 November 2025 that TR appeared more aware of interventions by undertaking his own examination, as a result of which he requested a repeat paediatric neurology review. The conclusions of that review were that TR looked more awake on examination and spontaneous movements in his left leg could be either executed wilfully or simply random re-positioning. However, the disorder of consciousness still fell between persistent vegetative state and minimally conscious state.

33. Dr C reviewed a video recording of TR apparently triggering his ventilator, which may have been an indication of TR breathing without assistance. He concluded, however, that because of a clear discrepancy between inspiratory and expiratory volumes shown on the monitor, the triggering was likely to be caused by an endotracheal tube cuff leak, not by TR.

34. When questioned, Dr C confirmed that he does not believe that TR has a conscious awareness of pain and he does not require sedation or pain relief. Occasionally, TR is given paracetamol but predominantly to treat temperature instability. He further confirmed that TR has not yet suffered seizures. Neither he nor the 'vast majority' of nurses have witnessed coughing; recordings of coughing may represent misinterpretation. He is of the opinion that TR does not have a cough response.

35. When considering the burdens of ongoing treatment, Dr C identified physiological harm such as lung damage, tracheal damage, a risk of pneumonia, ongoing *Clostridium difficile* infections, and a risk of skin breakdown, despite optimal care.

36. SR is TR's mother. He is her only child. She is married to TR's father but they are separated. Nevertheless, she describes being 'united in our love for TR and our concern for what is best for him'. She states that she has a very good relationship with the medical professionals treating TR. Since his admission to intensive care, she has remained at TR's bedside, sleeping in accommodation made available for parents at the hospital. She attends to all of TR's personal needs, e.g. washing, dressing, and changing him.

37. From her own observations, and conceding that 'I am not a clinician and I cannot be medically certain about TR's level of awareness, hearing or vision', she believes that TR shows signs of awareness and responsiveness that are not constant but 'meaningful to me as his mother'. She has seen him open his eyes, blink, change his

facial expression and appear more alert at times, as well as sometimes responding differently to familiar voices. This has all increased over recent weeks, particularly in music therapy. She believes that TR shows awareness of, and connection with, her. She says that generally TR appears calm and settled.

38. SR reminds me that TR has lived longer than was expected, and predictions of his imminent death last year fortunately proved to be wrong. She thinks he is now relatively stable and should be allowed to live, given that he is not suffering. She rightly says that his ventilator settings have not significantly increased and he has not recently developed any major complications. She describes TR being provided with 'relatively minimal treatment'. She regards the medical prognosis as 'uncertain' whilst acknowledging that TR is 'extremely unwell and unlikely to breathe independently again'.

39. She states that she believes that life and death are determined by Allah, not by human decision. Her faith and identity as a Muslim, which she also chose for TR, should be respected. The withdrawal of treatment goes against her deep beliefs and would cause 'immense spiritual distress and lifelong emotional trauma'.

40. She attended the hearing in person for both days. In answer to questions, SR reminded me of her daily care routine for TR. She told me, 'I think he definitely senses my love, he knows I am there'. She said TR enjoys her talking and laughing with him, with the music on. She is sure he can sense her touch. She asked that if he is not in pain and he is stable, why should he die? She said that the improvement can be seen just by looking at him.

41. She emphasised that she had been told that he was not going to get better but she has not witnessed that happening. Last April and May, she believed TR would die because 'he looked really bad' but he has improved since then; he moves his tongue and mouth, and he blinks. In the last two to three weeks he has moved his eyes: 'When I first come in sometimes he is sleeping, I touch him and says 'TR' and he opens up his eyes'.

42. RR is TR's father. TR is his only child. He lives and works in Libya, but has been travelling to Cardiff regularly to see TR and also spends time with him remotely by video call. He describes TR as 'my whole world' and says that every decision that he takes is guided by his belief in what is in TR's best interests.

43. He acknowledges that he has been told that TR's condition is critical and severe, but points out that TR has lived 'far longer than originally predicted' and he believes TR has been stable for extended periods. He believes that TR demonstrates some level of awareness. He states that TR has previously proved medical expectations wrong, for

example, in previously being able to walk, and it 'remains a possibility that he could surprise us again'.

44. RR states that he is a practicing Muslim, believing that life and death are determined only by Allah. He states that withdrawing TR's treatment would violate his faith and personal beliefs, and undermine TR's religious identity.

45. RR was also able to attend both days of the hearing in person, and give evidence with the assistance of an interpreter. He had taken the trouble to write down what he wanted to say and read it to the court. He told me that he accepts that TR is very ill and may not recover, but medical evidence is uncertain and he has shown improvement since last May. TR now moves more and shows breathing effort. This is not a straight line or continuous decline. There is no clear evidence that TR is suffering and the concerns of the doctors are mainly about what may happen in the future. TR has already shown that he does not follow expectations.

46. It is a serious concern for him that Dr Majumdar had referenced the resource implications of continuing treatment and queried whether his experience of Leigh's syndrome is sufficient. He reminded me that his religious belief is important, that faith has taught him that life is sacred and should be protected where there is doubt.

47. Natalie Robinson is TR's children's guardian. She has filed a comprehensive, sensitive and independent analysis of TR's best interests. As well as reading the evidence filed in these proceedings, she has spent time with TR on two occasions, spoken to both parents and Dr C, and been present on both days of the hearing.

48. Ms Robinson observes in her report that it is not possible to know what TR's wishes and feelings would be in relation to the continuation of long term ventilation and other invasive life sustaining treatment. Even if TR is unable to feel pain, she accepts that this invasive treatment over an extended period of time may impose an unacceptable burden upon him, a burden that may increase over time with little benefit.

49. Having spoken with both parents, she considers that they each believe that recovery, or at least improvement to some degree, is feasible for TR, despite the unanimous medical opinion. I note that this contradiction is also apparent from the evidence that they gave to me, in writing and orally.

50. It is her own professional opinion that, although it is completely understandable that the parents want more time with TR, the overwhelming medical evidence does not support this approach. It is likely that any such delay is not in TR's best interests if the burdens of treatment, as explained in particular by Professor Playfor, are likely to increase. She considers that TR has received excellent care since admission to hospital, but neither this care, his parents' love, nor their faith or hope, has enabled him, or will enable him, to recover. She accepts the medical evidence that TR's brain

damage is incapable of repair. Despite the parents' views and their faith, and acknowledging the strong presumption in prolonging life, where there is no prospect of recovery and TR's life is severely impaired, in her opinion it is not in his best interests to continue life sustaining treatment.

51. Ms Robinson told me that her written opinion had not changed at the conclusion of the hearing. The combination of irreversible brain damage, no cognitive awareness, no chance of recovery and the burden of treatment all presented very strong evidence that continued treatment is not in TR's best interests.

52. In arriving at this outcome for TR, she acknowledged that he was 'surrounded by love' from his family, and that the care provided by his mother is 'exemplary'. The calm and positive environment at hospital is largely due to mother's approach; she has centred her life around TR. She accepted that the parents take meaning from TR's continued life, and their faith (and the religious identity they wanted for TR) formed an important part of her consideration following her discussions with them.

ANALYSIS

53. Having reviewed the evidence, I remind myself that I must decide objectively which of the treatment options is in TR's best interests. In doing so, TR's welfare is my paramount consideration. His best interests encompass medical, emotional and all other welfare issues. There is, of course, a strong, albeit rebuttable, presumption in favour of preserving life. I must consider not only the evidence of doctors, but also most importantly the views and opinions of TR's parents, including their religious beliefs. The mother's observations are of particular value, given that she has spent so much time with TR since his admission to hospital.

54. In my judgment, there is an overwhelming core of indisputable evidence that is consistent throughout the medical opinion. It lays bare the disconnect between the relentless, downward progression of TR's illness and the perceived stability or perhaps improvement in his presentation that is particularly cruel for his parents. It is a tragic consequence of his illness that at times, TR may appear relatively (but superficially) well, thereby giving his parents false hope that he can and will defy the odds that are so heavily stacked against him.

55. The diagnosis of Leigh's syndrome is not in doubt. As Dr C explained, it has been confirmed clinically, radiologically, biochemically and genetically. I accept the wide body of expert evidence that has come to the stark conclusion that TR has suffered irreversible brain damage which has resulted in no cognitive awareness and from which there is no prospect of recovery. He will not, therefore, regain cognitive awareness or the ability to breathe independently. Very sadly, TR finds himself in the

terminal phase of a fatal disease. The current absence of seizures does not detract from this prognosis. There is no treatment that will cure or attenuate the severity of his condition.

56. It is entirely understandable that TR's parents will seek what little comfort is available from his discordant presentation. I had the privilege of meeting TR at his bedside. He is a beautiful young boy with a full head of glossy, dark brown, curly hair. He was impeccably clean and tidy, and very nicely and neatly dressed in a light blue suit of jacket and trousers, with dark blue suede sports shoes. He seemed very comfortable, and had a neutral, peaceful expression. The walls of his room were covered with colourful paintings, his shelves were full of birthday and other greetings cards and the foot of his bed was occupied by numerous soft toys. There is no doubt that he brings joy to his parents and wider family, who all love him very much. They are rightly proud of him.

57. TR's mother and others have described what they perceive to be responses to her presence, to touch and to sounds. Although Professor Playfor noted a modest degree of neurological improvement, I accept his opinion that such observations are entirely consistent with the continued absence of cognitive awareness and TR's inability to experience pleasure. I also accept Dr Majumdar's like opinion that individual, isolated observations of minimal neurological function must be put in the context of the wider picture. Put simply, the observations do not have the significance that it is entirely understandable that TR's parents would wish to ascribe to them. Other observations, in my judgment, either have a rational explanation (e.g. cuff leakage causing triggering of the ventilator) or are misconceived because they are so entirely inconsistent with TR's neurological damage (e.g. reports from music therapy).

58. The main characteristics of TR's illness (the irreversible brain damage, the irreversible inability to breathe independently, the absence of cognitive awareness that will not be regained and the inability to experience pleasure) in my judgment all weigh heavily in the balance against the benefits asserted by the parents in the continuation of the current regime of treatment. I set against that powerful body of evidence the parents' strongly and genuinely held views against the withdrawal of treatment, the adverse impact on their right to family life with their only son, and the importance of their Islamic faith in which TR was also to be brought up.

59. I accept the professional opinion that treatment is burdensome for TR. Burden, however, is not to be conflated with pain. Professor Playfor concluded that it is impossible to be certain if TR experiences discomfort or pain, but it is likely that he does not given his state of cognitive awareness. This is the overwhelming majority opinion within the body of medical evidence, which I accept.

60. In my judgment, even in the absence of a likely pain response, Professor Playfor is right to identify the physiological burdens of continuing treatment as follows:

(a) pneumonia,
(b) worsening respiratory failure,
(c) bone disease due to osteopenia (secondary to lack of load-bearing),
(d) associated pathological fractures and the development of renal stones,
(e) scoliosis with associated cardio-respiratory impairment,
(f) progressive gut failure,
(g) seizures that become increasingly difficult to control seizures,
(h) a risk of infective complications and sepsis.

61. In my judgment, it cannot be in TR's best interests to wait for these, or any of these, likely burdens to manifest or become acute before consideration is given to ending treatment that is otherwise incapable of alleviating or halting the progression of his fatal illness. In this, I agree with the carefully reasoned professional opinion of TR's children's guardian, as well as the medical experts and clinicians.

62. In conducting my holistic, objective analysis of TR's welfare, it will now be apparent that I have come to the conclusion that it is not in his best interests for life sustaining treatment to continue. I do not in any way seek to minimise what TR's mother has described as the 'immense spiritual distress and lifelong emotional trauma' that will result for the parents as a result of my decision, but in my judgment TR's welfare demands the course that I shall approve.

63. I shall therefore make the declarations sought by the applicant with a view to approving an up-to-date plan for the introduction of palliative care.

POST-SCRIPT

64. For apparent good reason, I have been invited by counsel for the parents to give 'guidance' about some procedural issues that have arisen in this case that may be of general application. However, I decline so to do because it would, in my judgment, be an unnecessary distraction from the relentless focus on TR's welfare that is the purpose of this judgment.