



Neutral Citation Number: [2023] EWHC 1997 (Fam)

Case No: FD23P00049

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 30 June 2023

Before :

MRS JUSTICE MORGAN

Between :

**ALDER HEY CHILDRENS NHS FOUNDATION
TRUST**

Applicant

- and -

[1] D

Respondents

[2] E

[3] C

(A child, by his Children's Guardian, Kay Demery)

Mr Parishil Patel KC (instructed by **Hill Dickinson LLP**) for the **Applicant Trust**
First Respondent - Litigant in Person
Mr Peter Mant (instructed **through Advocate**) for the **second Respondent**
Ms Katharine Scott (instructed by **Cafcass Legal**) for the **Guardian**

Hearing dates: 19 and 20 June 2023

Approved Judgment

This judgment was handed down remotely at 10.30am on 30 June 2023 by circulation to the parties or their representatives by e-mail.

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MRS JUSTICE MORGAN

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, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mrs Justice Morgan:

1. Between 29-31 March and 3rd April 2023, I heard an application by the Trust for a declaration that it is in the best interests of C, now 14, to
 - i) discontinue life-sustaining treatment, namely the withdrawal of ventilation; and
 - ii) receive palliative care.
2. The Trust's application was supported by C's Mother and by his Guardian. It was opposed by his Father whose primary submission was that C was not significantly cognitively impaired, there was still hope of his recovery and life sustaining treatment should continue. His submission in the alternative was that I should adjourn the application so that further evidence could be obtained from independent experts in paediatric neurology and paediatric critical care.
3. After hearing considerable evidence from C's treating clinicians and from his parents, I gave a judgment adjourning the Trust's application and acceding to the application for independent expert second opinion evidence to be obtained. This judgment is to be read with and as a continuation of that judgment.
4. On adjourning the case for further evidence, I also made orders in relation to ceilings of treatment in the interim period.
5. Reports were subsequently obtained from Dr. Patrick Davies, consultant in paediatric critical care, dated 4 May 2023 and Dr. Martin Smith, consultant paediatric neurologist, dated 21 May 2023. Both experts support the conclusions of the clinical team at the Trust that it is in C's best interests not to continue life-sustaining treatment.
6. On 12th June I heard remotely and refused an application which had been made by e mail on 7th June on behalf of the Father for a further nerve conduction study.
7. During 9th and 10th June C suffered a life-threatening episode of sepsis and a prolonged fall in his blood pressure. He was treated, within the parameters of the ceilings of care, and gradually recovered. He has continued to be treated for a serious infection associated with his Broviac line and was clinically stable by the time this hearing started.
8. On 19th June I resumed the hearing of the application which had been adjourned. No party had changed their position from those reflected at [2] above. The representation has remained unchanged save for the fact that Mr Patel KC is now instructed for the Trust, it having always been known that the adjournment would result in a change of counsel. I have again at this hearing been assisted by the highly skilled and sensitive representation. The Mother, whose case aligns squarely with that of the Guardian and the Trust, remains unrepresented.

Evidence at the Resumed hearing

9. At this hearing I heard evidence from:
 - Dr K (C's treating PICU consultant).
 - Dr Davis (Consultant Paediatric Intensivist instructed as an independent expert).

Dr Smith (Consultant Paediatric Neurologist instructed as an independent expert).

It is not my intention to set out in full the evidence I have heard from those witnesses but to make reference where necessary to that which has been of particular assistance or influenced my thinking. I have read carefully the thorough and detailed reports from Dr Davis and Dr Smith. The evidence I have heard at this hearing I have thought about in the context of and alongside the evidence I heard at the earlier hearing and which is reflected in my earlier judgment.

10. Before hearing the evidence of the independent experts, I heard evidence from Dr K who had filed an updating statement. At the time he wrote that statement it had been the case that whilst Dr K's overall view as to prognosis and the outcome which is in C's best interests had not changed, he reported that C had experienced a more prolonged period of stability than previously had been the case. However by the time he came into the witness box, that had changed since there had been the life-threatening episode at [7].
11. As to C's overall condition Dr K's view is that he had plateaued generally rather than improving and said he thought it important in thinking about stability and improvement not to disregard the recent episode when '*he nearly died*'. What that episode meant to him is that C is extremely fragile and susceptible to deteriorations which are very profound and unpredictable. Explaining the pitch of the concern he had when he was telephoned at home in the early hours of the morning of 10th June he said, "*It was very serious. I advocated that I thought it would be vital that his family came to see him.*" He thought C might well die. With very good intensive care by about a week later C had made a recovery back to his condition before the crisis – save that he has had to have his Broviac line removed which is where the infection triggering sepsis had been located.
12. He had discussed with neurology colleagues in the last week, and they had reported his status had not changed. He did not take any issue with Dr Smith's report in which he described the prospects of clinical improvement as remote because that chimed not only with his own view but with the consensus of neurologist views both internally at Alder Hey and also the external views from Manchester Children's hospital. He would defer to neurology expertise as to whether C would remain ventilated and immobile.
13. Whilst he did not agree that C was pain free he had analysed carefully the pain scores and regarded his pain as better managed with more instances where the recordings reflected days when there were no or fewer observations of pain. I will consider elsewhere in this judgment the question of C's pain and its relevance to the decision to be made for him.
14. There have been more signs of respiratory effort. Dr K's view was that these were nowhere near the level to indicate he could be weaned off mechanical ventilation. Taken to an entry in which a different consultant had noted that C's breathing should be challenged off the ventilator twice a week, he agreed that it had not been done at that level of frequency but rejected the suggestion that the fact that he had taken a different approach to what he called '*one consultant's view*' in challenging at a lesser frequency did not mean there had not been monitoring by challenge of C's breathing '*diligently, frequently and carefully*'.
15. Dr K was not willing to agree that the respiratory efforts were to be interpreted as a direction of travel towards C being able to breathe for himself and said that at best it would be anticipated he would always need some respiratory support and worried that it may also destabilise him if in an attempt to wean him off he were not ventilated enough. Dr K thought that, were he insufficiently ventilated, C will sense that he was not ventilated. Within this context and talking of occasions when he had been off the ventilator for assessment he observed, '*There have been times when he has almost*

looked distressed and panicky when he has not had ventilation in assessment. ' As I later reflected on that part of his evidence it seemed to me that an appreciation of how having his breathing challenged was experienced by C might lie behind his seeming disagreement that it was necessary to do it as frequently as another of his colleagues had identified.

16. There had been progress, albeit in small way, with feeding. Whilst it didn't in his view give him confidence that C was likely to be able to move to be taken off TPN since his calorie requirement still far exceeded even the increased amounts, he agreed that it was positive.
17. He agreed that he was aware and derived pleasure from his family. It was difficult to say at what level he derived that pleasure, but he certainly agreed that he did. He had watched the more recent video clips and readily agreed that they showed C responding to jokes made by his Father.
18. Dr K's own view as to C's situation and prospects overall was unchanged from that which he had articulated when he previously gave evidence.

Independent Expert Second Opinion Evidence

19. Dr Davis has been a consultant in Paediatric Intensive Care in Nottingham Children's Hospital since 2008. He was head of service for the department between 2014 and 2020 and is clinical lead for the East Midland's Paediatric Critical Care Network (a position he has held since 2021). He is an Honorary Associate Professor of Paediatrics at the University of Nottingham. He has prepared a thoughtful and detailed report which I have read carefully.
20. He was asked to give an opinion on four issues:
 - i) The prospects of C being discharged from ICU, to High Dependency Unit ('HDU') and then onto a hospital ward and ultimately into the community.
 - ii) The prospect of C being discharged into the community on Long term ventilation ('LTV').
 - iii) Whether he would recommend any further interventions or changes to C's care.
 - iv) Whether continuation of ventilation and other life sustaining treatment is in C's best interests.
21. He watched the videos taken by C's Father and spoke to all involved with his care as well as to both his parents. He had available to him and read the medical notes, including the nursing notes and the multidisciplinary team notes as well as the recordings of C's pain scores.
22. He examined C on the Paediatric Intensive Care Unit in Alder Hey Children's Hospital. C was awake and his observations were in the normal range. As part of his examination at a point when he was bending C's right elbow Dr Davis noted that he grimaced. Dr Davis had seen that at about the time he arrived with a nurse he had asked C to poke his tongue out in answer to a direct question and C was seen to make efforts to do so. C did not make a clear response to any other question he asked during his visit.
23. There have been recorded both before and after the last hearing efforts by C to take a breath they remain at a level which is insufficient to enable him to breath unventilated. As part of his examination Dr Davis challenged C's breathing. He set out this aspect of his examination in detail as follows: *I challenged his breathing. I took him off his ventilator and put him on to a bagging circuit. He was completely apnoeic for over two minutes, whilst awake with his eyes open. His saturations were maintained (with oxygen as CPAP). After two minutes he began to show very small breaths on the ETCO2 monitor, which were not discernible when viewing his chest, or the bag. They were showing as ETCO2 readings of around 2. When I put him back on the ventilator, his starting ETCO2 was 7.3, and this gradually came back down*

with continued ventilation. He made some grimaces during this process, but was generally calm.

24. As to C's level of consciousness Dr Davis agrees that he does not have "locked in syndrome": this refers to patients with intact cognition, who are paralysed in almost all of their body, usually sparing eye movements. C in contrast to that is able to make voluntary movements above his neck, including eyebrow raising, poking his tongue out, blinking, shaking his head, and smiling. Dr Davis's view, from his own observation and informed by his interviews with those who care for him, is that C is unable repeatedly and consistently to use these movements to communicate.
25. This raises two possibilities in Dr Davis opinion: either that he has intact cognition, but is unable to use his above neck abilities to translate this into communication, or he has severely impaired cognition, which he can only use to communicate intermittently. Dr Davis's view is that the first option is unlikely, as there is no muscular reason why he would be only able intermittently to respond to commands and questions. The "diffusely, severely abnormal" activity revealed on EEG also aligns with the second option in his view. In relation to C's Father's belief that his status is explained by the amount of medication he is on, Dr Davies agrees that there are a lot of medications (he listed 18 in the body of his report) and that they include sedatives and painkillers. The clear message from all professionals is that without these medications, C experiences what Dr Davis describes as '*clear, continuous distress*'. C has been much more settled since an optimal level of sedation and analgesia has been achieved for him and to withdraw that medication so as to test the effect on the level of consciousness is not something which would be acceptable. Dr Davis is of the view that he has severely reduced cognition and that therefore he experiences a commensurate reduction in his ability to interact with the world around him.
26. Of C's respiratory function Dr Davis reported as follows: *His respiratory function is extremely poor. For effective breathing to occur, four mechanisms must work simultaneously: a patent airway, lungs, muscles, and a drive to breathe. C's airway and lungs are not problematic. It is however very difficult to decide whether it is his muscle weakness, or a lack of a drive to breathe which are limiting him at the moment. His generalised lack of truncal muscle function would indicate that muscle power is the problem: however when I tested him off the ventilator, tiny efforts did not kick in until after over two minutes of apnoea, indicating a superadded drive problem. I suspect that he has both problems simultaneously. The muscle problem is however due to the innervation of the muscles, not the muscle fibres themselves. I note that he has been able to trigger a ventilator for a short time. Triggering needs small respiratory movements which cause brief reduction in pressure in the ventilator circuit, which is a long way away from effective breathing. Muscular training of respiratory muscles is only really effective for muscular fibre weakness.*
27. In his oral evidence when he was asked about the prospects of C being able to come off mechanical ventilation and breathe for himself he said he was '*light-years away from effective ventilation*'.
28. Dr Davis noted that there have been multiple efforts to get C to feed enterally and was aware of the continued efforts to encourage him to feed. Nothing in his opinion was out of step or differed from the evidence I had already heard from C's treating gastroenterologist, Dr P, and his other treating clinicians. In his report Dr Davies reflected on the difficulties of introducing feed: *I wonder if the neuropathy affecting his body has also affected his gut, and he has a weakness of peristalsis meaning his ability to handle feed is restricted. The only way to show this is by increasing his feeds until any ceiling is reached.* Asked about the recent greater success at the slow increase in feeds which are being better tolerated, his view was that since what was being tolerated is about 20% of his normal feed volume but at half strength it is essentially '*trophic feeding*'. He acknowledges that there is a plan to increase very slowly. Increases of the order of 5ml per hour per day even if successful were not

such that gave him optimism that C could move away from TPN feeding. In common with the evidence I had heard from others, he expressed concerns about TPN feeding which has a limited life span and he observed in his report that *TPN hepatitis is an inevitable consequence of long term therapy.*

29. Dr Davis had been asked to give a second opinion on C's prognosis. In his report he expressed that opinion as follows: *C's prognosis can be ascertained by two routes: his diagnoses, and his trajectory. His diagnoses are all clinical. These are by their very nature less precise, and therefore less prognosticable, than diagnoses made by scientific tests. Steven-Johnson Syndrome and Critical Care Polyneuropathy are clinical descriptions of the end points of processes which are poorly understood. This means that it is very difficult to give a clear description of prognosis for his neuropathy. We know that such neuropathy can take many months (up to two years) to fully improve, but I would not be able to say who is going to improve, when, or why. It is therefore correct and judicious to give C time, and lots of it, to demonstrate whether he can, or will make any improvement. For C therefore, his trajectory is of utmost importance. Patients with Critical Illness Polyneuropathy can improve for up to two years after the initial insult, but the trajectory of improvement is not zero to one year, then full improvement after. C has had no improvement at all of his muscular function since his weakness evolved, 14 months ago. It is extremely unlikely that he will now start to recover.*
30. A feature of C's presentation at the time I gave my earlier judgment was the detection on repeat electromyogram of a weak signal. In the ten days before this hearing I had heard an urgent application by the Father for an order that there should be a repetition of that test. It was an application which was opposed by all other parties. It was also not supported by Dr Smith, the independent paediatric neurologist instructed to give a second opinion, as I will come on to consider. I refused the application. It is right to record that at the time I refused the application, C's recent life-threatening crisis meant that his condition was such that those treating him would not have carried out the test on ethical grounds in any event. It is a procedure involving sedation. Mr Mant had, however, heralded at the time of refusal the possibility that he would wish to revisit the question of a repeat test of neuro conductivity with the independent experts.
31. Dr Davis (who on this broadly deferred to Dr Smith) had considered the relevance of the findings in coming to a view on prognosis: *The novel finding on repeat electromyogram of an extremely weak signal is noted. This is the lowest possible reading, and of questionable significance. It has not been followed up by any clinical improvement. I will leave it to the neurologist expert opinion to decide on whether this should be repeated. The meaning of any further test results should be discussed prior to the test being done. In my view, his clinical progress is more important than more investigations.*
32. In his oral evidence he remained of the view that though he deferred to Dr Smith on matters of neurological expertise, as to prognosis the signal finding has to be seen in the context of his overall clinical picture. Within the body of his report as to prognosis he continued: *Sadly, C's prognosis is bleak. There is general agreement that he has made no appreciable progress since August 2022, nine months ago. The therapy team is clear that there has been overall deterioration in his function. I note Father's optimism regarding his feed and his breathing: however his feed is still of extremely low volume, and of negligible nutritional value, and his breathing is nowhere near enough, either muscularly or by drive, to sustain life. I understand Father's wish to "leave no stone unturned", however C has undergone multiple attempts at establishing feeding and ventilation. It is always possible to try one more time, without real justification.*
33. As to prognosis, and despite proper challenge on behalf of the Father, he did not depart from the opinion he had expressed in his report. He thought it difficult to be sure of C's level of awareness though like Dr Smith he would regard him as in a minimally conscious state. His view remained that C's level of cognition, though

untestable, was severely diminished. His thinking in this respect was influenced by the factor that were it not so he would be more consistently reliable in his responses. Though he was not dogmatic in this respect since he accepted that there might be a component which was C choosing not to cooperate. Reminded of the evidence from Dr L that there might be the prospect that C was just '*pissed off*' he observed that also was something that could not be measured.

34. His conclusion on prognosis is that for neurological improvement it is bleak. C has made no appreciable improvement for the past nine months. The question of life expectancy is more difficult since it is dependent on complications of intensive care given. Dr Davis had given following view: *He has had frequent episodes of sepsis, from which he recovers relatively quickly. However, intensive care complications are inevitable, and depending on the seriousness of these, he may have a fatal complication. He is currently having expert care, where he is in extremely good condition considering his illness, and the length of time he has spent in hospital. There is no imminent risk to life. Without any intensive care complications, his life expectancy cannot be estimated, as it is essentially open ended. With a fatal intensive care complication, the risk is that he would suffer a painful, distressing, and uncontrolled death.*
35. He did not depart from that view in oral evidence but he did expand on it. The complications inherent in intensive care life, he explained, happen at intervals and what would cause his death would be one of these. It might be a blocked tube that causes his death, it might be liver failure, infection is always going to be a complication, those are examples of what may bring about his death as a complication of intensive care. It may happen in five years or ten years, or it might be much sooner as C doesn't have a condition with a clear deterioration he is completely static and at the moment stable but the rapid deterioration over 9th/10th June shows what can happen. Dr Davis regarded it as impossible to give a life expectancy, with high quality care he could have years.
36. He expanded also on what a death which he had described in his report as 'uncontrolled' meant in reality. In a sobering passage of his oral evidence he said this: *"Dying from being unwell is very different from a managed death. It's terrifying. His heart rate will raise, whatever level of consciousness he has he will realise that he is suffocating. His whole body will fight if it is an infection. If it is a pneumonia affecting lungs he will be unable to breathe."*
37. As to the prospects of C being discharged from ICU, to HDU and then onto a hospital ward and ultimately into the community Dr Davis was of the view that there was no realistic prospect. He could not be discharged even to HDU without an improvement in his condition and it was his opinion that there was no realistic prospect of a meaningful improvement. The combination of his very high nursing load, ventilator needs, intravenous nutrition, intravenous medications, and a long list of drugs, of which some are intravenous was one component of what makes such a discharge unrealistic but as with all else in this case it is a question of taking account not just of the component parts but the whole. C is completely flaccid, requiring significant nursing input for all cares. Reduction in his nursing level would put him at risk of skin deterioration, creating more episodes of sepsis, pain, and distress. Discharge on long term ventilation into the community he regarded as impossible. His approach to physiotherapy was, to the extent that it fell within his area of expertise, slightly different. Since it has general benefits for the body if it could be done without pain and distress he would not see any reason not to but he would not see it as rehabilitative, and he was explicit that it changed neither his opinion nor his overall recommendations.
38. His overarching view was that if C remained on life sustaining treatment that would be as an intensive care patient in the ICU. His remaining life would be in intensive care and at some time in the future his life would end there as a consequence of an intensive care complication. He said in his oral evidence that the thought that C's

“chances of a meaningful recovery are zero. When pressed he said he thought that there was a non zero chance he may be able to flicker a finger but able to sit up, work a joystick and cognitive ability and consciousness that is a whole other level than the flickers we are seeing with his breathing”.

39. His oral evidence did not alter his opinion in his report that: *“In my view, he will not improve from this situation. Therefore prolonging intensive care would only serve to continue his suffering, as per RCPCH guidance 2a, 2b, and 2c. Continuation of intensive care is unethical, and he should have careful, compassionate, palliative care.”*
40. Dr Smith has been a Consultant Paediatric Neurologist at John Radcliffe Hospital, Oxford, since 2015. Before that he had for 9 years been a Consultant Neurologist in Birmingham Children’s Hospital. His routine work encompasses all aspects of acute and chronic child neurology, but his special interest lies in neonatal neurology, cerebral palsy, movement disorders, and rehabilitation. Instructed as an independent expert in this case he has provided a thorough and detailed report.
41. He examined C on 9th May 2023 in the company of a nurse who has known and looked after him throughout his admission. He elicited an immediate response from C when he asked him to open his mouth and stick his tongue out. On examination there was not even a flicker of movement in any muscle groups in the upper or lower limbs. Reflexes were also absent.
42. Dr Smith’s attention had naturally been drawn to the improvement in the repeat nerve conductivity study carried out in January 2023. His opinion was not supportive of the Father’s application made on 7th June for a repeat of such a study. In his oral evidence, he emphasised the importance of not viewing different aspects of C’s presentation in a compartmentalised way and that the reading which had been achieved in January had to be seen in the context of clinical presentation. He accepted when asked by Mr Mant that there must as a matter of logic be a point in time at which what was detectable as an electronic reading had not yet translated itself into clinically observable improvement. However what was useful to him in clinical terms in looking at C was that now, in June, months on from the nerve conductivity test, there was nothing which indicated any improvement. He did not in his oral evidence depart from the opinion he had given in writing: *“I note that there was modest improvement in the repeat nerve conduction studies performed on C in January 2023. This is not surprising as the body will always make efforts to repair itself following injury (as was seen on the nerve biopsy in May 2022, revealing some attempted remyelination), but there is no evidence that this is functionally beneficial. As noted in my clinical examination there is not even a flicker of movement in the limbs, and I note when seen by Dr Davies that ventilatory effort was negligible. As there is no evidence of clinically meaningful improvement in the limb weakness after a period of over 12 months, my view is that it is extremely unlikely that will be any further clinically meaningful improvement, and therefore C will remain immobile and ventilator dependant for the remainder of his life”*
43. Having so expressed himself when giving his written opinion he said at this hearing *‘I regard it as unlikely bordering on negligible that there will be recovery in terms of clinical power from the nerve signal seen in January’*
44. When pressed, appropriately, in cross examination his opinion was that the best-case scenario was that there might be a 5% chance of a flicker of movement in a finger sufficient to flick a switch in a movement with gravity eliminated. In giving this evidence he was clear that this percentage chance did not mean that it was his view it would happen and nor was there anything on which he could draw to support the estimation of the chance.
45. His opinion is that C has neurological impairments of both the central nervous system and the peripheral nervous system. Both aspects are extremely serious and in combination yet more so.

46. Critical illness neuropathy accounts for the disorder of the peripheral nervous system. It is his view that the respiratory failure is likely to include involvement of the phrenic nerve leading to paralysis of the diaphragm, the muscle primarily used for breathing, as well as the intercostal muscles in the chest needed in combination with the diaphragm.
47. A critical illness neuropathy alone, he might expect to have a good prognosis for recovery albeit not full recovery. A critical illness neuropathy would not be startlingly uncommon – he spoke in terms of seeing perhaps 3 or 4 a year. It is the complexity of C’s conditions in combination which puts him into a different category. Along with the time which has elapsed with no clinical sign of improvement.
48. He did not see evidence of injury to C’s brain stem which would account for the difficulty in respiratory drive. He was not sure that there was in reality a difference of view between himself and Dr Davis and was not suggesting Dr Davis was wrong, but he felt the involvement of the phrenic nerve was the more likely explanation for C’s inability to breathe for himself. What matters is that C is unable to connect the respiratory drive from the brain to the muscle of breathing.
49. In giving his written opinion he had drawn attention to the paucity of literature relating to long term outcomes in severe cases of critical illness neuropathy in children. Whilst there is more information to be found in relation to adults there are difficulties extrapolating outcomes in children. In the main body of his report he said this: *“I should highlight to the court that in my review of the literature I have been unable to find even a single case report of a young person or adult who was ventilated for over 12 months due to CINM. There are several potential explanations. Firstly, it is certainly exceptionally rare. I have never personally encountered such a devastating outcome from CIN. Secondly, if there are other cases it is possible that care would have been withdrawn at an earlier stage. Thirdly, there may be a reluctance for authors or journals to publish isolated case reports of very [poor] outcomes.”*
50. Against that background he readily accepted Mr Mant’s question that one should be cautious and the more so since C’s case is, in the experience of all who have been consulted, exceedingly rare and probably unique. It was not, he explained, that he disagreed at all with the need for caution before reaching conclusions, but his opinion was that after 16 months on a ventilator with no improvement there had been already appropriate caution. No one, including the Father in his discussions was suggesting that the present situation for C should continue indefinitely.
51. His clear opinion is that C’s condition is further compromised by the presence of acquired brain injury. By reference to the helpful reproduction of imaging he had included in his written evidence he explained the effect and impact of the demonstrable atrophy in C’s brain on the scans taken in March 2022 and then in January 2023. Considering this in the context of PRES in his written opinion he said: *“C also has a substantial acquired brain injury (ABI). This is seen on the series of brain scans, manifesting with widespread loss of brain volume (atrophy), in both the cerebral hemisphere (supra-tentorial compartment) and cerebellar hemispheres (infra-tentorial compartment). There is also a evidence of injury to the basal ganglia, which have shown abnormal signal on the MRI scans of April 2022, July 2022, and January 2023. Although I understand why the diagnosis of PRES was suggested, the MRI brain scan was abnormal in any event several weeks beforehand, and it is likely that there is permanent injury as a consequence of hypoxia and ischaemia +/- systemic inflammation.”* He has no doubt that the damage to C’s brain is permanent and irreversible.
52. Dr Smith’s opinion is that it is difficult to predict life expectancy for C. He agreed with Dr Davis both in the sense that he could live for many years and in the sense that it will be a complication of intensive care which will bring about his death. Whilst he agreed, he would nuance the view because the serious episode of 9th/10th June showed

that he may succumb even in the short term in the event of another serious episode of illness.

53. Added to this in the longer term there are factors which from a neurological perspective affect life expectancy and severe immobility is one such. Literature for high cord injury for example also suggests reduced expectancy – perhaps 14 years. The combination of profound neuropathy affecting the peripheral nervous system and a brain injury which is severe in his view makes those estimates optimistic but not impossible. Dr Smith explained that in that context he had quoted in giving his opinion 10 –15 years but it could be shorter or longer. Moreover he explained one should not disregard the possibility that he could die on a ventilator whether by a misadventure with for example blocked tubes or otherwise. His own clinical experience included looking after another child who had *‘just slipped away peacefully on a ventilator’*.
54. Dr Smith gave helpful and detailed evidence on C’s level of consciousness. On occasion the terms cognition and consciousness have been used as if interchangeably in discussion about C’s level of awareness and responsiveness. Dr Smith assesses him, by reference to the 2013 Report of the Royal College of Physicians publication into Prolonged Disorders of Consciousness as in a Minimally Conscious State: *“A minimally conscious state may be characterised by inconsistent but reproducible responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings.”* More recent refinement has subdivided to with and without speech, but C’s situation precludes speech. Dr Smith’s own observations of C and his discussions with those who had looked after him for many months led him to that conclusion.
55. I had wondered when hearing C’s level of consciousness described in that way, whether it might not be understating it having watched (with a layperson’s eye) the videos. I therefore found it very helpful to the understanding of C’s level of consciousness that Dr Smith had also included within his written opinion, again by reference to the literature, potential behaviours seen in a patient of minimally conscious state
- *Follows simple commands*
 - *Gesture yes/no answers*
 - *Make intelligible verbalisation*
 - *Vocalisations or gestures in direct response to a question’s linguistic content*
 - *Reach for objects that demonstrates a clear association between object localisation and direction of reach*
 - *Touch and hold objects in a way that accommodates the size and shape of the object*
 - *Sustain visual pursuit to moving stimuli*
 - *Smile or cry appropriately to linguistic content of emotional but not to affectively neutral topics or stimuli*

That list of behaviours has resonance at least in so far as C’s condition permits its application. Dr Davis likewise regards him as fulfilling the criteria of MCS.

56. His level of consciousness he thought likely to undergo a modest improvement over time by which he explained that he meant it is possible that the reproducible but inconsistent responses might become more consistent and might allow him to make some choices, if he could head turn reliably so he could operate a switch to indicate choices. Dr Smith observed *‘I am not saying its likely but it’s possible’*. He was unable to say how likely an improvement might be but if it happened at all he estimated it would be at the level of allowing him to make simple choices such as *‘I’d like to wear the red pajamas’*. All of this, however, Dr Smith reiterated was on his part not what he offered by way of expert and informed opinion but an educated guess.

57. Dr Smith had reported as to the prospects of C making a recovery as follows: *“C’s critical illness neuropathy is more severe than I have personally seen in my clinical practice, and indeed I am not aware of any similar cases in the medical literature. As he remains totally paralysed in all four limbs and ventilator dependant the chances of clinically meaningful recovery are remote. It is very likely that he will continue to need a broadly similar level of medical and nursing care for the remainder of his life.”*
58. In evidence he was asked about the possibility of C being weaned off long term ventilation and gave an estimate of something like 1-2%. He remained of the view that he did not think it likely and would defer to the intensivists. It would not completely surprise him however if in 12 months C could tolerate short periods off the ventilator with a non-invasive mask. He was by no means confident C would be able to tolerate it at all but he could not dismiss it.
59. When he had been instructed, Dr Smith had been asked to comment on a worst-case scenario for C from a neurological perspective. There had been follow up questions by agreement sent on behalf of the Father in which he had been asked to consider the best-case scenario from a neurological perspective. His response, from the sense of which he did not depart in oral evidence, was telling: *“As discussed above best and worse outcomes are subjective, but I will attempt to answer this. I am restricting my answers to what I consider medically plausible, even if unlikely. It is possible that there will be modest improvement in his level of consciousness. However, as discussed above I expect C will live with substantial learning difficulties. It is possible that there would be some further improvement in his peripheral neuropathy leading to limited and partial limb movement, but I doubt this would change the fact that he would always need full time nursing care. I doubt it would be possible for him to be fully weaned from longer term ventilation, but it is theoretically possible. In the scenario that his critical illness neuropathy recovers to a large extent (which I consider to be improbable), this would likely then allow an underlying movement disorder (due to acquired brain injury) to declare itself. On this basis alone, he would very likely still require full time nursing care.”*
60. As to that last aspect, in oral evidence, he explained what he had in mind is that, ironically, it is likely that the neuropathy, from which he doesn’t expect a recovery now, is protecting C from the physical effects of spasticity and prolonged muscle contraction he would otherwise be experiencing from the serious injury to his brain.
61. Dr Smith remained of the view which he had encapsulated at para [89] of his report : *“I have found reaching a view on C’s best interests exceptionally challenging, especially in light of the wide difference in opinion between his parents. However, after giving the matter careful thought, and having in mind that a) no clinically meaningful improvement is likely, and that b) there is a high chance of long term distress and suffering from his exceptionally high burden of multi-system illness, I have come to the conclusion that continuation of ventilation is not in C’s best interests. I believe that if asked for their view, the overwhelming majority of Paediatric Neurologists practising within the UK would reach the same conclusion.”*
62. Before leaving the witness box he emphasised to me that C’s condition embracing the critical illness neuropathy and injury to his brain was more severe than any he had encountered personally, or in the any published literature, or in informal and anonymous discussion with colleagues. The overall constellation of problems was, he said, *‘up there with the worst’*.

Discussion

63. It is necessary for me to determine C’s best interests and whether I should make the declarations sought in the context of two stark options:
- i) Continued provision of life sustaining treatment in the form of ventilation and other care and treatment within a Paediatric intensive care unit setting.

- ii) Withdrawal of life-sustaining treatment in the form of ventilation with the inevitable consequence that C's life will come to an end.
64. There is in this case no prospect of C being moved to care at home or even in the foreseeable future of being stepped down to care from ICU to the HDU. That is the consensus of all medical opinion. At this hearing Dr Davis instructed as an independent intensive care expert to give a second opinion said that there is no prospect of a discharge from ICU in his current condition. I accept his evidence on that. By way of context he added, "*I know of no one in the country who is anywhere near as dependent as he is who has been able to be discharged*".
65. There is no evidence as to any view expressed by C about how he might feel to be in the situation in which he now finds himself or something akin to it. At thirteen years of age the thought of it had probably never crossed his mind. There is no possibility of ascertaining his views now. The completely polarised views of his parents about what he would want or feel about his present situation mean that there is nothing which I can safely draw from those views in reaching a final decision.

Burdens and Benefits

Benefits

66. I give very considerable weight to the preservation of life. It is a strong factor in favour of continuing the ventilation which C needs to keep him alive. I have already considered in my earlier judgment the question of C's religious background and beliefs. In thinking about the strong presumption in favour of the preservation of life, I hold in my mind the evidence to which I have alluded in that judgment as to the Faith into which he is both baptised and confirmed. It is relevant that it is a Faith which has as a central tenet that life is sacred. Neither aspect means that the very powerful presumption is irrebuttable.
67. There is good evidence which no one seeks to gainsay that C is aware of and takes pleasure in the company of his family. The video clips on which the Father relies and I described in my earlier judgment have been followed by others which again show C responding to jokes and smiling. This factor is for me one which attracts very significant weight in the analysis.
68. Dr Smith's evidence was that he considers C to be in a minimally conscious state though towards the upper end of that state. He had, when he saw C, elicited a response to a single step command but not a repeat thereafter. In coming to his view as to consciousness, he has taken account of the videoclips of C's responses to his family at his bedside. He did not regard the clips which showed, for example, C smiling at nonsense words made up by his Father to amuse him or responding to a punchline of a joke as inconsistent with his view that this was a minimally conscious state. Those sorts of responses led him to the view that he was towards the upper end of it. Though he did not think that C was consistently responsive, taking together what he had observed with what he had seen and read in preparing his report. This he regarded as an issue of consciousness rather than cognition since C did have the ability to respond on those occasions when he did. In relation to the prospect of any change in that minimally conscious state, when asked he gave the view that he might expect if he saw C in 5 years' time on a best case that his level of consciousness might have improved to the point where his responses were consistently given. This was another part of his evidence in which this witness felt himself to be entering the territory of an educated guess because of the uncertainty of C's condition and the possibility of further episodes of illness having an impact on already uncertain cognition but he was confident in saying that as to consciousness, he would expect improvement over time. I therefore add to the benefits balance that C might be able, on a best case over time, to have a level of consciousness which allowed him more reliably and consistently to make responses to questions. I had considered, in listening to Dr Smith's evidence on this point whether the possibility of a greater level of

consciousness might carry with it the prospect of a greater awareness of his situation which might not so readily fall within the benefits side of the balance. I have, however, cautioned myself against an unduly speculative and overly subjective approach. Furthermore, a level of consciousness which had the effect of more consistent responses would be directly referable to the pleasure he takes in his family.

69. It is also important in this case, just as fell to be considered by Poole J in *Pippa Knight* at [80] -[82] by reference to the approach of Macdonald J in *Raqeeb*, to place into the analysis of the benefits that C's life has inherent value to his family. In contrast to the child Poole J was considering, C is aware and takes comfort from the presence of his family. He is precious and valued to all of his wider family on both sides. Unusually, this aspect might seem less straightforward than one might expect. There can be no doubt that each of his parents love him dearly. His Father I am entirely sure sees his life as having inherent value in this way. His clear view is that C is 'still in there' though he will never return to the boy he was. His Mother's position is more nuanced. She has told me several times during the hearings in this case not only that she regards C's situation as not a life and certainly not a life he would wish to live but also that the state in which he is kept alive is terrible and unbearable for all of her family. I understood her as saying that her own perception is that C's life no longer has value to him rather than I should understand her as saying his life has no inherent value to her. I am fortified in this by my recall of a time in the Mother's submissions in March when she had incorporated into her passionate explanation of why she thought he should be allowed to die the words 'I don't know what I will do without him'. I have taken those poignant aspects of what the Mother has said to me into account when I conclude without doubt that C's life is of inherent value. The affecting way in which those who have cared for C in so dedicated a way over such a long time have spoken about him demonstrates that his life has touched theirs on a personal as well as a professional level. It must also follow from the rarity of his combination of illnesses and medical conditions that much will have been learned from his life, his experiences on ICU, and the experience of those treating him during discussion at multidisciplinary levels in and out of the hospital where he is treated.

Burdens

70. The assessment of C's pain is a particularly difficult aspect of his situation. I have set out in my earlier judgment the extent to which C appeared to those treating and observing him to be experiencing pain. I do not repeat but remind myself of those parts of my judgment, notably [89]-[91] in which I have considered the issues of pain and discomfort. At this hearing Dr Smith whilst by no means dismissing the observation of those who are looking after C, from the field of his own expertise had little difficulty with the proposition of neuropathic pain but was hesitant to commit to how it was, neurologically, that C would experience transmitted pain in circumstances where his central nervous system was not working so as to transmit pain from a stimulus. Couched, as was all his evidence, in terms which he chose carefully so as to try to avoid distressing yet further C's family, he said that C's lack of feeling and sensation in his trunk and limbs meant that if one were to try deliberately to cause him pain by an external, objectively painful stimulus, he did not think it could hurt him as he would not expect C to feel it. He did think it possible that there might be some explanation for pain to be found in smaller fibres of the peripheral nervous system for which it is impossible to carry out any conductivity testing and so impossible to know anything about transmission of sensation. He emphasised however, on this and on other occasions, that he was making an 'educated guess'. He was not cross examined about other pain which is documented as experienced by C in connection with for example gastrointestinal issues about which I have heard evidence from those concerned with his nutrition.

71. By the time of this resumed hearing C's pain was better managed. Mr Mant put to Dr Smith and submitted to me that whatever might be the debate about pain scores recorded, and whether he is experiencing episodes of mild to moderate pain or discomfort on a basis that could properly be described as 'frequent' given the large number of 'zero' scores, he is not suffering excruciating pain such that in and of itself would weigh so heavily as a burden as to tip the balance in a way that is determinative. In circumstances where his pain is well controlled the Father submits it does not represent a burden. I do not agree that for it to find its place in the balance pain must be excruciating or even constant.
72. I have earlier reflected on the difficulty of disentangling the concepts of pain and discomfort from distress [92] and [93]. At this hearing consequent on Dr Smith's hesitation to commit to an understanding of transmitted pain I asked Mr Mant whether in the event that I on that basis accepted his submission that C was *not* experiencing pain as a burden, it must mean that those physiological and other indicators – grimacing ; squeezing tightly closed his eyes; sweating; raised heart beat – must be interpreted as indicating significant distress. Mr Mant's eventual position was that on taking the evidence as a whole, it remained the position that it was not always reliably possible to distinguish between pain and distress. I agree with him about that.
73. Dr Smith's evidence about pain is important. Were it the case that it enabled me confidently to conclude that C is not in pain, then when I consider the burdens of him continuing to receive life sustaining treatment, it would not be one of them. I do not however regard his evidence as establishing that. In so concluding my thinking has been influenced by the following:
- i) Pain is a complex concept and a particular specialism. The observations which record it are intended as objective but inevitably carry with them a degree of subjectivity. They are, however, the recordings made by those who are familiar with C and have been looking after him for a considerable time. They are also the recordings of those whose specialism means they are familiar with the environment of paediatric intensive care and the ways in which pain is both manifested and managed in that environment. I accept the recorded observations over a long period of time that C experiences episodes of pain consistently but not constantly and that that pain can sometime be managed but sometimes it cannot.
 - ii) The evidence of recordings sits within the context of other evidence I have heard –notably of the pain and discomfort which some though not all handling caused to C – active physiotherapy being the most stark example. It is notable that as recently as 9th May, Dr Davis noted C grimacing when his elbow was bent as part of the examination.
 - iii) The evidence of Dr L the clinician whose expertise lies in pain management and has responsibility for C was unequivocal that he experiences pain that is difficult to manage and has not been successfully managed. She regarded any pain as unacceptable and explicitly C's pain which remained unmanaged as unacceptable. I accept her evidence and the effect of it. I do not regard it as diminished by the fact that by the time of the resumed hearing there had been, as she had hoped with a new background medication, overall an improvement in the management of his pain.
 - iv) The observations of pain are ones which have featured throughout. Including at a time when there was no suggestion of any attempt at a breathing effort or any result detected on a nerve conductivity test.
 - v) Dr Smith, who alone amongst the clinical and medical witnesses raised a question about the extent to which C's neurological state might transmit pain did so in a way which gave the impression that he was perplexed from a neurological standpoint rather than that he was saying that those who made observations and who gave evidence from other disciplines were wrong. I also note that he made specific reference to the limbs and trunk, and I bear in mind

that one of the aspects of C's situation which is so awful for him and for everyone else is that he cannot communicate what it is that is hurting or distressing him.

74. I have not ignored what his parents say about his pain. They are neither clinicians nor instructed experts, but they are the ones who know him best. Inevitably their views come with their own perception. The Mother gives a description of him being in significant pain and described the expression of it as unbearable to watch of C screwing up his face. The Father takes the position that although he is sometimes in pain he is usually pain free and comfortable. It is unusual to have such diametrically opposing perceptions from the two people who love him most. They no doubt see him at different times and in different parts of his day. Accepting as I do that they each describe what they see in good faith, I have found it safer in considering his pain to rely more on what is observed by others who are not family members. It is also the case that their expressed views, irreconcilable though they may be with each other, are congruent with pain that is sometimes managed sometimes not.
75. I have thought carefully about the evidence I have heard about pain. It remains the case that those professionals who are caring for C do not regard his pain as satisfactorily managed. His requirement for background pain management is well established and the fact that he has any breakthrough pain is something that is regarded as close to a failure of pain management. The life-threatening episode (as I accept it was) on the 9th –10th June illustrated that pain is and will be an ongoing feature of his life. On that occasion when his physiological condition became so precarious that he could not have administered his usual background pain medication that was reflected in heightened pain scores in the following 24 hours. Within the documented pain scores for the months of April; May and from 23 May to hearing there are days when there are no recordings of him being in pain: 4 in April; 1 in May and 5 in the period from 23 May to this hearing. It obviously cannot be said that he is in constant pain. Nor however can the characterisation urged by the Father at this hearing of 'usually' pain free be right. I am satisfied that pain, howsoever explained neurologically or caused, continues to be a consistent part of C's life. It falls to be considered in the burdens both of his condition and of his treatment.
76. Elsewhere I have considered the way in which there are episodes of distress not associated with anything which is assessed as causing pain. They are striking and distressing observations. I agree and accept that it would be speculative to try to determine the precise cause of his episodes of distress. I am satisfied that evidence of C crying, for protracted periods when he is inconsolable is something which falls to be considered as a burden of his underlying conditions. I so conclude whilst recognising that anti-depressant and other medication has been deployed in an effort to mitigate it.
77. The unanimous view of the clinicians and medical experts is that there is no realistic prospect that C will be able to leave the Intensive Care Unit. I have been reminded in oral evidence that the ICU is not a calm and peaceful environment but quite the reverse. It is a busy, noisy place filled with machinery and devices required for the very seriously ill and the frequent urgent interventions required to preserve life in those who are critically ill. He will continue to require invasive procedures. He may or may not be able to understand what is being done to him or why. I have heard at this hearing that for example deep suctioning is a procedure which is unpleasant. It is not clear how in the light of his condition he experiences it. It has been noted that even in relation to suctioning of the back of the mouth, C is described as withholding his cooperation. It is hard to know what to make of that but taken at the lowest, it seems to me logical to proceed on the basis that it does not bring him pleasure. A nurse who knows him well told Dr Smith that he dislikes it.
78. Lying in the ICU he cannot see. He is unable to leave the ward or room. Whilst at this hearing Dr K agreed that were there improvement, he would be willing to consider trying again to move C by use of a hoist to sit in a chair which would be a better

quality of life than lying in a bed that has to be seen within the context of the evidence of prognosis. The evidence to date is that C's conditions in combination have made it impossible for him to sit in a chair without suffering significant discomfort. Moving him is a difficult and lengthy process, complicated by his dependence on mechanical ventilation and his entirely flaccid state, which I accept causes physiological responses including a raised heartbeat and profuse sweating. Since his physical condition means that those responses do not come from physical effort on his part they are to be understood as indicative of the effect on him of the experience. I accept the evidence that the efforts made on one occasion to take him, in his bed, outside so as to feel fresh air on his face was so problematic that it will not be repeated.

79. The fact that the rest of his life will be lived in the ICU is something which weighs in the balance as a burden. The prospect of an unplanned and unmanaged death in the intensive care unit is another. The powerful evidence of Dr Davis as to the reality of such a death I have discussed earlier and I accept it. The prospect that C would die in circumstances which this expert described as '*terrifying*' with every likelihood that he would not have his family with him, would not hear their voices and know they were there and instead would be alone and frightened is as bleak a prospect as could be imagined.
80. C's Mother has spoken movingly of the compromise of his dignity. In the Appeal of the decision of Poole J in *Pippa Knight* the Court of Appeal left open the consideration of where dignity as a distinct concept finds its place, if at all, in the analysis in this sort of case. In C's case the Father strongly urges me not to engage with consideration of dignity and the other represented parties agree in a more muted way. I agree that whereas it may be necessary in some other context for the concept of Dignity to be explored, it is not in this case. Ms Scott however, says that those matters to which the Mother draws attention when she speaks of dignity, using that word as an ordinary English word, rather than in any legalistic way, are not ones which I am precluded from considering when I think about C's situation from his point of view. Indeed she submits that I should so consider them. I am satisfied that those aspects have been sufficiently considered in the foregoing paragraphs.

Conclusion

81. It does not surprise me that every professional and expert witness from whom I have heard evidence has at some point told me that C's situation has been the most challenging, complex and difficult they have encountered or had to express an opinion on. I have been struck also by the fact that all of them, experts in their respective disciplines and well used to having charge of the care of patients with extremely serious illnesses and conditions, have given evidence in a way which carried with it a sense of how they had agonised over what might be the outcome for C and a tangible distress at his situation.
82. The medical evidence overwhelmingly supports the conclusion that C is in a minimally conscious state. On the spectrum which is embraced by that term I accept the evidence of Dr Smith that his ability inconsistently to respond means that he falls towards the upper end of it.
83. The fact that there is no professional or medical evidence which supports the continuation of life sustaining treatment as in C's best interests is important but the assessment of what is in his best interests by consideration of the burdens and benefits of his life – flowing both from his underlying conditions and from his treatment - is for me. Assessment of those best interests embraces the wider welfare and social aspects of his life and those aspects are very significant matters the benefit attaching to which are capable of displacing, according to the circumstances of a particular situation, countervailing burdens in determining best interests.
84. I have found this an immensely difficult conclusion to reach. C's level of awareness exceeds that of children in respect of whom similar declarations have been sought

from the court in the reported authorities. It is this level of awareness which enables him to take comfort and pleasure in the company of his family when they visit him. He is on occasion responsive to what is said to him by smiling and I accept, as did Drs K, Smith and Davis that he is responding to more than simply the tone of voice. Those aspects of C's life which Dr Davis described as '*flashes of joy*' are prominent in my consideration as I assess the burdens and benefits of it. Within that context he is able to derive comfort and pleasure from life. The flip side of that is, however, that his level of awareness means he has some awareness of his situation.

85. The point has been made to witnesses during this hearing that there are people whose disabilities mean that they are unable to move or communicate beyond eye or face movements; that they live dependent on ventilators forever. That they live requiring, and so dependent on, the assistance of others for all their basic and intimate needs of living. That there is no prospect of them ever living in any other way.
86. Mr Mant returned to this point in submissions; that there are many severely disabled people who endure many of the sorts of burdens which C must bear and may have very limited ability to experience positive interactions with their environment and that their lives are not to be regarded as without value. Against that measure, neither should C's.
87. In part I have had to grapple, because of the way in which Mr Mant makes that submission, with the question '*what is a life?*' If there is no prospect of meaningful recovery - and I accept that there is not on the overwhelming totality of the medical and expert evidence, including that of the second opinion evidence which I permitted on the Father's application- what then? What does it mean from C's perspective if he will always be ventilated, always be wholly dependent on others for everything, have no agency or ability to control his life and always be subject to the burdens which I have considered in detail but yet will continue to have flashes of joy. Are those flashes of joy in the balance sufficient to outweigh the burdens of a treatment regime which does not offer him recovery and of a condition from which he is not expected to show any clinically meaningful improvement. I understand why it is felt important to couch submissions about C in the way Mr Mant has done, but I have held in my mind that to the extent that it may be being suggested that I should ask myself the question '*what is a life?*' that is misplaced. If the question or something like it is to be asked as part of my assessment of his best interests and analysing the benefits and burdens then it is really '*what is this life for C?*'. I am not in this case considering or seeking to determine any wider philosophical issue. I am making a best interests decision for a boy who finds himself in a situation which I regard as uniquely tragic.
88. In my judgment having considered all of the evidence which I have heard and read and balancing all of the relevant factors, I am satisfied that it is not in C's interests to continue to receive life sustaining treatment. The burdens of his underlying illness and clinical conditions and of the intensive care treatment needed to keep him alive taken in combination drive me to the conclusion that it is not in his interests to continue to bear those burdens in circumstances where I accept the unanimous view of all those medical professionals and clinicians whose evidence has been placed before the court that there is no hope of meaningful recovery. I am satisfied that whilst he has the ability to derive comfort and pleasure from the company of his family the very substantial burdens of his illness and his treatment outweigh that benefit. Prolonging his life would prolong for him the bearing of those burdens. In reaching that conclusion I take account of the exceptional care he has received and would continue to receive at Alder Hey PICU. I take account also of the (conflicting) wishes of those who love him most. I must however take an objective view of C's best interests from his point of view and with his welfare in the widest sense as paramount.

Declarations

89. For the reasons given I am satisfied that it is in C's best interests to withdraw mechanical ventilation and contrary to his interests for it to be continued. On withdrawal of mechanical ventilation, it is anticipated that C will live a very short time. There will be defined limits on the treatment to be provided to him which will be set out in the order following on from this judgment. This is not a case in which it is practicable for extubation to take place other than in the Intensive Care Unit where C has been cared for to date. I have no doubt that the dedication and commitment shown by Dr K and his team throughout will extend to doing all they can to ensure that C will at the time his life sustaining treatment is withdrawn have beside him, and know that he has beside him, those who love him and wish to be with him.
90. C's Mother and Father have each fought tirelessly and at enormous emotional cost for what they each sincerely believe to be right for their much-loved boy. Neither could have done more. Neither has, or should feel they have, responsibility for the decision which is mine.
91. The declarations sought and which I will make are not in contravention of C's Article 2 right to life. To the extent that they are an interference with C's (and each of his parents') Article 8 right to family life they are a necessary and lawful interference.
92. The declarations I make are that it is lawful and in C's best interests that
 - i) Life sustaining treatment in the form of mechanical ventilation should be withdrawn
 - ii) He should receive palliative care
 - iii) There should be clearly defined limits on the treatment provided to C after the withdrawal of mechanical ventilation with the effect that he should be allowed to die.

Postscript.

During the week following the hand down of this judgment, C died peacefully within a very short time after the withdrawal of mechanical ventilation,