



Neutral Citation Number: [2023] EWHC 2000 (Fam)

Case No: FD23P00049

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 30.06.2023

**Before :**

**MRS JUSTICE MORGAN**

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**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)**

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**Mr Ian P Brownhill** (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: 29, 30, 31 March 2023 and 3<sup>rd</sup> April 2023

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**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. This application is brought by a hospital trust for the following declarations:
  - That it is lawful and in best interests of C, a 14 year old boy, to receive: (a) Compassionate extubation of ventilation;
  - (b) Standard cares including suction;
  - (c) Palliative care including pain relief and sedation.
2. As is self-evident from the nature of the declarations sought, at the heart of this case there is a family facing a situation of desperate sadness; parents having to contemplate circumstances no parent should have to contemplate and a child who lies gravely ill. This has been a difficult hearing for all concerned. It has inevitably involved consideration of a great deal of highly specialised and technical medical and clinical evidence. It may have seemed to those who love this child and who sat through that difficult and often very distressing evidence that we in this court room may occasionally have lost sight of the fact that it is all about him. I repeat here what I said to his parents at the start of the case. Even if it may sometimes seem so, no one has lost sight of that. I have held in my mind throughout this hearing that right at the centre of everything is their child.
3. It has been the express wish of one of C's parents that he should not in this judgment be given a pseudonym but should be identified by a random initial only. So it is that he is referred to throughout as 'C'

The Parties Positions at This Hearing

4. In outline form the parties' positions are as follows:
  - i) The trust has reached the conclusion that C has no meaningful prospect of recovery and that the burdens for him of continuing life-sustaining treatment outweigh the benefits.
  - ii) C's mother believes that C's ongoing treatment is contrary to his best interests. She has come to the view that he has no quality of life. She does not believe that he has any prospect of recovery or improvement. She is firmly of the view that continuing treatment is causing him pain distress and suffering. As a component of that she has made specific reference to the way in which his dignity is compromised because he is wholly dependent on others for his most basic needs.
  - iii) C's father does not agree that C is cognitively impaired, though he recognises that some of the drugs used to treat him make it difficult sometimes to gauge his responses and understanding. He is firmly of the view that there is still hope of his recovery even and although that may be a long and drawn-out process and that therefore treatment should continue. A component of his thinking though not advanced as the headline point of his position is his own Roman Catholic faith and his belief that life – and so here C's life – is sacred. His primary position is that I should make a declaration that it is in C's interests to continue to receive life sustaining treatment. His secondary position is that I should adjourn before reaching a final conclusion and permit him to obtain expert evidence in the form of independent second opinion report(s).
  - iv) The Guardian, Ms Demery after much consideration and following discussions with each of his parents and with members of his treating team, takes the

position that C's quality of life is impaired by his circumstances and the continuation of life sustaining treatment is not in his best interests.

5. So it is that the matter comes before the court. An application was not made until January 2023 because it had been hoped it could be avoided. There have been discussions and meetings at which those who treat C, his parents and wider family have sought to reach agreement about whether it is in his interests to continue to receive ventilation. The Trust's ethics committee has met and given its own conclusion. Best interest meetings and reviews have been held. In respect of one discipline second opinions have been sought by the hospital to feed into that process. Since in the absence of consensus an application has been made to the court it must be determined. In making the determination I hold in my mind that the power of the court is to decide whether the course proposed is lawful or whether it is unlawful. Specifically, since during the course of the hearing the parents have each made references to what 'anyone' would want for themselves or their child, I make it explicit that I have not allowed to infect my thinking consideration of what I might wish were I, or someone I cared about, in C's position. The question which I must decide is what is in C's best interests.
6. C's condition makes this an exceptional case even amongst the cohort of applications which come before the court for such declarations. Another unusual feature of it is that the dispute is not between the medical profession on one side and the parents on the other; or even the result of differing conclusions reached by clinicians but arises essentially between his parents. C's mother is supportive – in a positively active sense rather than weary resignation – of the approach invited by the Trust and the Guardian. C's father is passionately and strongly opposed to it.

### Background

7. In February 2022, C who was then 13 fell ill. He had recently recovered from Covid 19 which he had had the previous month and had made him feel unwell but which he did not seem to have had terribly seriously and apart from that he had previously been in robust good health. C developed a rash at the end of February and was taken to his local hospital on 27<sup>th</sup> February. The rash got worse, and he went back the next day. He was admitted and the working diagnosis was Steven-Johnson Syndrome and later there was a working diagnosis of Toxic Epidermal Necrolysis (TENS). These are both autoimmune response conditions which manifest themselves as blistering and degradation of the surface of the skin. The distinction that tips broadly similar symptoms from one diagnosis to another is one of degree. Where up to 30% of the skin is affected, it is characterised as Steven-Johnson Syndrome. Where it exceeds 30% it meets the definition for TENS. It is an incredibly painful condition; such that dressings applied to the skin sometimes must be changed under anaesthetic. That has been the case here. In C's case 90 % of his body was affected. He was transferred for admission to a major teaching hospital. The working diagnosis of TENS was confirmed by skin biopsy. Those who have been responsible for his care are confident in the diagnosis but remain uncertain of the precipitating cause. It is thought most likely either that it is linked to his infection with Covid 19 or that it is linked to a reaction to ibuprofen. Following his transfer, he was, on 5<sup>th</sup> March, ventilated. That is to say reliant on mechanical means to maintain his breathing. He has remained ventilated throughout the period save for two occasions when attempts have been made to extubate him. Neither has been tolerable and he had to be reintubated.

8. Another consequence of the breakdown of the integrity of the skin is that it defeats one of the main functions of the skin which is to keep the body safe from infection. Those with TENS are therefore vulnerable to infection –notably sepsis. On 15<sup>th</sup> March C had an episode of septicaemia. His temperature reached 43 degrees centigrade, and he was established on a renal support machine. He had overt multiorgan system failure. Three days later C developed low blood pressure and experienced major bleeding from many sites including his mouth. An MRI scan carried out on 23<sup>rd</sup> March suggested a toxic neuropathy causing localised bilateral symmetrical signal change affecting the dentate nuclei within the deep cerebellar white matter. Those treating him were unable to identify a clear cause for these non-specific changes. From this time on there has been persistent hypertension requiring monitoring and management. On 29<sup>th</sup> March 2022 –so exactly one year before this hearing commenced – the most recent attempt was made to take C off the ventilator. It was unsuccessful.
9. By early April, investigations into his condition by CT and MRI scans were suggestive of Posterior Reversible Encephalopathy Syndrome (PRES). The following day he had a suspected epileptic seizure. On 8<sup>th</sup> April C required a tracheotomy under general anaesthesia. He underwent an MRI scan on 28<sup>th</sup> April in part to investigate what might be the cause of his poor respiratory drive. No abnormalities were detected on the brain stem to explain this, but what could be seen was an improvement in PRES compared to the previous MRI. Along with the presentations detailed thus far, C was, despite a calorific intake exceeding his daily requirement, losing weight markedly and so he was referred to gastroenterology specialists.
10. By the end of April a nerve conduction study showed severe generalised polyneuropathy affecting both sensory and motor fibres, with evidence of acute denervation. To the extent that it was possible to test the relevant auditory areas of the brain there was no sign of response but it seemed that C was able to hear. That remains so to date. There is no dispute about this, and from some of the recorded clips of him produced as part of his father’s evidence which I have watched and which will be considered later in this judgment, it is clear that he has hearing. As to sight, it is thought that he retains some vision. On testing electrodiagnostically (undertaken much later in his hospital stay on 8<sup>th</sup> September) it was found that the study undertaken showed ‘abnormal visual’ which was thought to equate to him having ‘*rudimentary vision with likely at least some impairment and moderate retinal change*’. Those witnesses who were asked during oral evidence about this by his mother agreed with her description of him as ‘*functionally blind*’.
11. His difficulty in taking nutrition continued and on 20<sup>th</sup> May C began to receive this nutrition via total parenteral nutrition (TPN). That method of delivery carries with it not only the obvious risks of infection but also in the longer term is well recognised as being harmful or at least potentially harmful to the liver. Which is why, if other methods of delivery can be found it is generally preferred to avoid it. It could not be avoided for C. In the period from June to October, attempts were made to reintroduce enteral feeds. Those attempts were unsuccessful and were accompanied by pain and discomfort for C. Although he cannot speak, he is able to express when he is in pain and at this hearing I have heard graphic descriptions of how he does this by grimacing, moving his head, squeezing his eyes tightly shut, clenching his mouth or by crying.
12. It could not be understood why there was pain associated with feeding so on 21<sup>st</sup> July an oesophago-gastro-duodenoscopy (OGD) and colonoscopy was carried out under general anaesthetic. This was normal to the naked eye. The biopsies to his oesophagus

showed some changes, but these were not significant and did not explain his gastrointestinal symptoms. By October the attempts at enteral feeding were discontinued because of the burden those attempts placed on C and the lack of any positive outcome for him from that burden.

13. Towards the end of July a further MRI of his brain and spine revealed generalised loss of volume in the brain suggestive of atrophy. He was however, as a more positive sign, by the middle of August noted to show some respiratory effort. A further nerve conduction study carried out on 16<sup>th</sup> August showed severe generalised polyneuropathy affecting both sensory and motor fibres with no evidence of reinnervation.
14. At a clinical decision-making support meeting on 24<sup>th</sup> August C's case was discussed. One of the descriptions given to that meeting was that C was described as appearing pervasively sad day to day with episodes of pain every day. Within the material provided to me in advance of this hearing I had read already of prolonged episodes of what appear to be a combination of pain and distress. The identification of 'sadness' at that meeting is congruent with parts of the evidence in which I had read of occasions noted by the nursing staff when C is noted for long periods to be crying without a cause that is obviously pain related and when he is inconsolable. At this hearing I heard from Dr L a consultant in palliative medicine that for her, these episodes in which she could not attribute or link his obvious distress with pain or with discomfort from some cause which could be identified and so alleviated were the most worrying aspects of C's presentation.
15. The conclusion of those at the meeting on 24<sup>th</sup> August was that C's prognosis was poor. The decision was made at a multidisciplinary team meeting following on 5<sup>th</sup> September to change the goal toward which the medical and clinical professionals with care for him were working from one of rehabilitation to one of maintaining posture. From Dr K at this hearing, I have heard how that change of emphasis was one which those working with him found helpful because, for instance, it impacted upon the physiotherapists' approach to the interventions they were giving him and the extent to which those interventions included handling and movement which was often causing pain. The necessity and purpose of pain and discomfort experienced for a rehabilitative goal was he said one thing but when the goal changed the balance of what was in effect inflicting pain and discomfort to no purpose tipped the other way.
16. On September 26<sup>th</sup> there was another episode of spontaneous effort of breathing. As on the previous occasion in August this was not at a level to maintain ventilation
17. During his time in hospital C had had a Broviac line inserted. By October it was necessary to consider whether to reinsert that line, a procedure which required to be undertaken under general anaesthesia. C's condition at the time meant that whether this should be undertaken was considered at a best interests meeting. The decision was that it should be, and it was inserted on 21<sup>st</sup> October.
18. The prognosis for C by November in the view of those treating him was poor and on 22<sup>nd</sup> November he was discussed at a Clinical ethics committee meeting. The unanimous view of the committee was that it would not be ethically acceptable to continue with Life Sustaining Treatment since this would not serve C's best interests. The conclusion of the committee was that he had *'no foreseeable chance of recovering from his severe and untreatable peripheral polyneuropathy and would remain dependent on ventilation to sustain life and because C suffers from significant amounts of distress, anxiety and pain when receiving therapy which is now not aimed at treating his condition, (rehabilitation), but aimed at maintaining his current condition and prevent further potential deterioration. As such, the burdens incumbent*

*on continued therapy, outweigh the benefits that would be gained from continuing with these therapies*

19. At a best interest meeting on 8<sup>th</sup> December the question of continuing life sustaining treatment was discussed. The clinical team and C's mother (and stepfather) were agreed it would be in C's best interests to withdraw life sustaining treatment and move towards palliation. This was not agreed by C's father.
20. Towards the end of December his Broviac line became infected and had to be removed. This led to detailed discussion, given the ethics committee and best interests meetings about whether it was right to put him through the procedure to replace it. In large part because there was an identified dispute as to best interests and that would have to be determined in the absence of consensus, it was reinserted on 10<sup>th</sup> January the view being taken that it would be wrong to pre-empt the decision. Proceedings were issued on 16<sup>th</sup> January 2023. The matter came before me in the urgent applications list. At that hearing I made case management directions and listed the matter for this hearing.

#### Developments between issue of proceedings and the listed hearing

21. In the period before the matter came on for hearing there were two developments. First a nerve conduction study on 19<sup>th</sup> January 2023 indicated a small electrical outcome which may on one interpretation be indicative of reinnervation; Second another attempt at a spontaneous breath was noted.
22. Following the conclusion of submissions and with the agreement of all parties, and exceptionally, late evidence was sent to me of further episodes of attempts at breathing when the ventilator was turned down, and of C responding to the presence of his family with smiles.

#### C

23. During his life before he became so unwell C lived with his mother and his step-father. His parents are separated. He spent a good deal of time also with his father and his step-mother. He is the only child of his parents, but he has two half siblings on his mother's side and three on his father's. As is the way of things, the characterisation of them as half siblings is neither here nor there and to him they are his brothers and sisters. C is at secondary school and had hopes – more rooted in reality than is sometimes the case – of being spotted by a scout to play football professionally. As well as being interested in sport, he had recently found himself more motivated to work hard academically because he was ambitious to study architecture and had realised that he would need the grades to do that. He had been both baptised into the Roman Catholic faith and had during his primary school years, so his father told me followed the path familiar to those of that Faith, of making his first confession; first holy communion and then being confirmed. He had as he became older practised his faith with a lighter touch.
24. There is a difference of opinion, or perhaps of emphasis, between his parents as to how significant a part of his life was his faith by the time he became ill, but it is not one which I need to determine. His father straightforwardly told me his son was a boy who believed in God. I will return to the way in which the father invites me to consider the question of religious faith elsewhere in this judgment. His mother is not someone who practices the Roman Catholic faith and told me that she had not regarded C as having any belief in God and certainly he never spoke to her of religion. I noted however with some interest that part of her evidence in which she described to me how in the early days of his illness she had come in to find the parish

priest at his bedside and blessing him. She told me that she had instantly worried that if C had woken up and seen a priest at his bedside he would have thought he was dying. That vignette inclines me to the view that whilst his mother does not see religion as something that was especially important to C, she recognised it as a part of his life.

### Competence.

25. C is now 14. Nobody has sought to persuade me that he is Gillick competent and so able to make the decision as to his future treatment. It is possible that in the earlier stages of his illness he may have been Gillick competent. I accept what has been the position of all parties at this hearing that if that were the case then, it is not so now and that he does not have competence to make the decision.
26. There has been anxious consideration given by the Guardian and relevant members of his treating team especially Dr L who has given oral evidence on the point, to the question of whether it would be appropriate to seek explicitly C's own view by exploring with him his wishes and feelings. There is evidence that he has been able to respond to clear and closed questions by communication tools such as blinking or sticking out his tongue. The extent to which he is still able to respond to that sort of question is in issue between the parties, but no one suggests he cannot respond at all. There are however very real uncertainties about the extent to which he understands, and his ability to understand nuance. His communication taken at its highest is very limited and would not permit a nuanced and difficult discussion such as would be required however sensitively undertaken to ascertain his wishes and feelings.
27. In her discussions with the Guardian, about the possibility of directly seeking to ascertain his wishes and feelings about continuing life sustaining treatment Dr L had not thought it an exercise that could be safely undertaken. Prominent amongst her thinking was the prospect of C who had previously been frightened by being in hospital being given however sensitively information that one possible outcome for him now was death. I had found her view on that and the way she expressed it difficult to square with what had been her written evidence in her report as to what should be the approach to C if he became more unwell and showed signs of active dying or were Life sustaining treatment not to be continued. This had been expressed in the following terms: *At this stage, it would be important to explain in simple terms that he was imminently dying and offer reassurance that his family were present, and we would continue to look after him*
28. I had not understood on reading it why she would regard it as important to explain to C that he was dying, and I found it even less easy to understand having heard her evidence about C's earlier fears. When I asked her to explain the thinking, her response was that what appeared in that part of her written report was not what she meant. In the otherwise uniformly excellent and careful evidence from the hospital this was unfortunate. Within the court room when consideration came to be given to that part of the report, there was a very obvious increase in the distress of family members present at the thought of someone telling C he was about to die. I have heard nothing at this hearing that suggested to me that it would be in C's best interests to be told, if for whatever reason the time comes, that he is imminently dying.
29. In the document prepared by counsel at the outset of this hearing the Guardian's position on ascertaining directly his wishes and feelings is expressed in the following way



- i) it is unclear whether C would be able to understand the information about the continuation or withdrawal of life-sustaining treatment and what that would mean.
  - ii) even if C could understand this information, there would be no way of him being able to ask questions or seek reassurance about what he was being told.
  - iii) further as C cannot reliably communicate on less emotive questions, it is unlikely that his views could be reliably obtained.
  - iv) thus the exercise has a high risk of causing significant distress to C, with little prospect of obtaining any useful information about what he wants.
  - v) for these reasons the Guardian has not explored with C his views on his current predicament and treatments.
30. I understand how it is that this very experienced guardian from the High Court team has concluded that it would be neither possible nor safe to seek directly to ascertain his wishes and feelings. Each of his parents agrees with that conclusion and neither of them would wish any exploration directly with him of his wishes and feelings to take place. That has remained his father's view notwithstanding his own position (and the evidence he produces to support it) that C is far more responsive than others who spend less time with him appreciate.
31. In the light of that collective position, I have taken the view that I should not (as I otherwise would) go to see C in the environment in which he is being cared for. An explanation would have to be given to him about who I am and why I had come to see him. The risk of distress to no purpose that such a visit would carry with it is obvious.

#### The Issues for the Court to Determine

32. The declarations Mr Brownhill seeks on behalf of the trust are as set out above. In determining C's best interests and whether in the light of that determination I make the declarations sought, I do so within the context of either:
- i) Continued provision to C of life sustaining treatment and ventilation mechanically in the setting of a PICU
  - ii) Withdrawal of life sustaining mechanical ventilation.
33. This is not a case in which there is a prospect of ventilation in a home setting. It emerged during the oral evidence that references to a 'home ventilator' are not to be equated to ventilation at home. Neither is there, because of the complexity of C's overall presentation the option on the evidence before me of a stepping down to care outside the PICU setting.

#### Evidence at this hearing

34. I heard oral evidence from
- i) Dr K consultant Paediatric Intensivist
  - ii) Dr L consultant in paediatric palliative medicine
  - iii) Dr M consultant neurologist
  - iv) Dr N consultant paediatric neurologist
  - v) Dr P consultant gastroenterologist
  - vi) Mr Q physiotherapist
  - vii) Mr R Paediatric Intensive care Charge nurse
  - viii) C's father and mother
  - ix) Ms Demery
35. In addition to the live evidence called I had the joint external opinion from Drs Varma and Desai consultant paediatric neurologists at another large teaching hospital dating from November last year which was in agreement with the neurological opinion on

- which the Trust relies, and a one paragraph updating report from Dr Varma obtained the day before this hearing started indicating that her opinion remained unchanged.
36. I was provided with and have read the best interest meeting minutes from the meetings held on 11<sup>th</sup> October and 8<sup>th</sup> December 2022; the clinical ethics committee meeting notes from 22<sup>nd</sup> September 2022 and the clinical decision-making minutes from the meeting held on 24<sup>th</sup> August 2022. Some but not all of the MDT meeting notes were available. A separate bundle of C's medical records had been lodged before the hearing. During the hearing a variety of other medical notes and records were produced including MDT notes, pain scores, OT notes, SALT notes and some but not all of the nursing notes requested. Mr Mant has made moderately pitched but proper complaint on behalf of his client that in a case such as this all relevant documentation such as for example the detail contained within the nursing notes should have been provided so as to permit a proper analysis of the burdens and benefits of continued treatment by an informed picture of C's day to day life.
37. Other than the reports from consultant paediatric neurologists at another teaching hospital there has not been in this case an external second opinion sought.

#### The Views of C's Family

38. I have heard powerful evidence from C's mother and from his father. They each of them told me about the boy he was as they each knew him and the boy he now is as they each know him now. The views of parents do not determine what is in a child's best interests but they are of significant value in the court reaching that determination so I have listened with great care to what they have said and read equally carefully the way their views have been expressed in writing. What appears in this judgment is intended to encapsulate those views not as verbatim replication.
39. His father told me that he visits his son 6 out of 7 days usually in the later part of the day. On the days he doesn't go, his wife goes and his other sons and his daughter also visit. He spends hours sitting with him stroking his face talking to him. Having what he called a laugh and banter across the bed about for example the fortunes of his local football team, to which his son shows a response. He agrees that C is in pain sometimes but not as much or as often as is suggested. He doesn't believe that the days of little or no pain are sufficiently recorded and that he thinks may skew the picture. The picture he sees is of a boy who is sometimes settled sometimes not *'if he wasn't settled and calm and was in pain and grimacing the majority of the time then we wouldn't be here'* he said early in his evidence. What is reported by the nurses when his wife makes the daily telephone enquiry is usually that C is settled. He does not regard that report as the nurses seeking to spare his feelings.
40. He doesn't agree that C is cognitively impaired although he does think it likely that sometimes when he is on strong pain killers it is likely to affect some of his responses. Essentially however the point for him is that C is cognitively aware and that as he put it *'my son is in there and if he wasn't aware that would be different but he is and there is so much there'*. This he said could not be clearer from the WhatsApp videos he exhibited to his statement.
41. He had seen the effort at a spontaneous breath on 19<sup>th</sup> January and provided a screenshot of the reading it is something he regards as important and worthy of investigation and the same goes for the fact that there has been as he put it *'a flicker'* on the nerve conductivity investigation. He very strongly disagrees with the decision to step back the physiotherapy. Having heard the evidence about an MDT meeting where Dr K had said there was discussion about C's nerve conductivity perhaps

improving to the point where he could use a joystick in a wheelchair he did not think that now was the time to give up.

42. What he wanted to convey however was that although he strongly felt that there were other investigations which should be done, he was not unrealistic. He knows that C is never going to be the boy who played football, went on camping trips, spent too long on his X box and had an expectation of an independent grown-up life. Towards the end of his evidence he said this:

*C has a really poor existence in life but a life all the same. I do not believe he would choose death over where he is right now. That might change ... It has been a horrendous 13 months to where we are now and if it goes on to another horror train that is elongating it. It cant go on for ever I know that but want to turn every stone*

43. E is a man for whom religion is important. Elsewhere I have set out his own view of his son's religious beliefs. I wanted to understand from him the role which from his perspective (whatever weight I might give it in the balance) religious belief should take. He confirmed what I had suspected; although he does regard life as sacred he does not say life-sustaining treatment at all costs. That is why in his written evidence he is able to contemplate circumstances in which he would 'let him go' and why in his oral evidence he was clear that if he thought C were in pain the majority of the time he would not oppose it. He explained to me that he believes in, and has latterly been furious with, God. He believes in, and hopes for, miracles. His faith, as he put it, is important but it runs alongside rather than leads the position he takes about whether Life sustaining treatment should continue for C.
44. C's mother in some ways had less to say since she agrees with and supports the position taken by the Trust but her evidence was no less affecting for that. She said that she felt in some ways guilty because here she was, a mother advocating for the death of her child. When first he had gone into hospital like everyone else, she had hoped for a recovery. She had not left the hospital for the first six weeks. She could not praise enough the doctors and nurses who have looked after him so well. As time went on however, she had realised that this hope was not going to be enough and gradually she realised he wouldn't get better. She had known in her heart that he was not going to recover even before the clinical decision-making meeting on 24<sup>th</sup> August. Since then, she thinks the reality is that C is dying and is being kept alive in a way that is cruel. She still visits him but goes now several times a week. Sometimes her daughter, C's older sister goes with her. His younger brother, with whom C has always had a close relationship, has visited but does not really understand what is happening. As a snapshot of the impact on the family as a whole she described to me how she had dissuaded her own mother now in her 70s from visiting C and had lied to her about his condition so as to protect her describing him as 'mostly sleeping'.
45. Although there were times earlier when C smiled she has not seen that for a long time. She is distressed and thinks he would be too by the situation in which he is now. She had not watched the WhatsApp recordings his father had made and felt very strongly that it has been 'disrespectful' to film him in that way for this case and to have him 'performing on command.' It was she said like he was not a person, and she did not think his father should have done it. When she thought about C before he became unwell she remembered how sporty he was and how proud she had been of his real ability on the football field. It was not just wishful thinking that he might have gone further with his football. She told me that even though he was only 13 he was also really serious about architecture and had asked about extra tuition. All of that life she

said was lost to him now. All he had was lying in a bed, blind, able to move his head a bit, put out his tongue. *'The only thing he can communicate'* she said *'is pain'*.

46. From the visits she has with C, she believes that he is always in distress or pain. Although she had heard the word 'settled' used at this hearing by others what that meant to her was that because he had needed morphine to kill the pain that had settled him. C's mother was especially keen that people should realise that his pain and his situation is being *normalised*. *'It is not normal to need morphine. It's not normal to be lying in a bed blind not able to move not able to even itch his nose or tell someone he needs to itch his nose'*. It was evident from the way she spoke that C's mother was distressed by the pain he is suffering as a result of his polyneuropathy, but the more her evidence continued, the more I had the strong sense that for her, at least as much if not more than the pain, it is the indignity of his situation which she regards as so intolerable. Her clear view is that C also would find – and she thinks is finding – it intolerable. Since he was quite a small boy, aged 7, he would not allow his mother into the bathroom with him. Each of his parents and both his step-parents described him as a shy boy. His mother says that he would find being washed and changed by nurses beyond difficult. He would be embarrassed, she said to be having his pads changed and to be reliant on a catheter. She couldn't imagine any 14 year old who wouldn't be embarrassed but she knew for sure C would. With just as much force and conviction as his father had said the contrary she said *'I know C wouldn't want to live like this'*.
47. She told me also that she believed C would be *'mortified'* at the distress the situation was causing to her and to his family. The last words he said to her when he was able to speak were *'mum don't worry about me I love you'*. She believes him to be either in pain or distress or both all the time. Occasionally now she might see him seeming to smile when he is asleep but that makes her wonder what he must feel on waking to his life. When she had visited during the days of this hearing what she had seen from outside the room before she went in was C lying in bed crying. She said that she had struggled to put into words how awful a situation she feels this is for her son and his family but said she thought the closest she could come was *'If this were an idea someone came up with for a film no one would make it because it is so terrible'*.
48. C's mother was also explicit that she does not support the idea of any further opinion about C's prognosis or likely improvement. She regards it as insulting to those clinicians who have given such clear and straightforward evidence to be doubting them. It is also in her view entirely pointless and just continues C's life of pain longer and for no reason. Although she had sat and listened to the discussion about whether C might improve to the point where he could operate a joystick in a wheelchair, she thought that was complete nonsense and was *'never going to happen'*. C is not even able to tolerate the pain of being moved to a sitting position and has not the muscle tone to support it even aside from the damage to his spine from the scoliosis.
49. From the written evidence I have also something of the view of his wider family- his uncle; his stepmother and stepfather; his brothers and sisters. Some of them have sat in court to listen and to help support his parents. The families align, nearly but not quite, with the views expressed by the mother and father. Not quite because the father told me that one of his other sons disagrees that C should be maintained on life sustaining treatment. The overall impression I have formed of the wider family view is that they all of them love C, he remains an important member of their family and they want the best for him but they have arrived at different views of what that is.

The Views Of The Medical Professionals

50. There is a unanimous view amongst all of the Trust witnesses that it is not in C's interests to continue to receive life sustain treatment and that it is in his best interests for it to be withdrawn. From those who amplified their written evidence orally at this hearing there has been no change to their collective view.
51. Dr K knows C well, he has cared for him since the second day of his admission to the PICU. He agreed that his case is unique in his and his colleagues' experience. Dr K summarised C's presenting problems as follows
- a. Toxic epidermal necrolysis - >90% Total Body Surface Area (TBSA)
  - b. Previous Posterior Reversible Encephalopathy Syndrome (PRES)
  - c. Ongoing neurology concerns - severe polyneuropathy; no improvement on repeat nerve conduction testing
  - d. Ventilator dependence via tracheostomy
  - e. Visual impairment-likely significant
  - f. Ongoing gastrointestinal problems including inability to feed
  - g. Episodes of distress/anxiety/pain
  - h. Essential hypertension
  - i. Transient low GDI 9 count- ? significance
  - j. Previous hypercalcaemia
  - k. Currently being treated for Central Line Associated Bloodstream Infection (CLABSI)
52. As to the last issue, CLABSI, this which it had been hoped was being effectively treated with antibiotics had, by the conclusion of the evidence worsened such that there was the prospect of another removal of a now chronically infected Broviac line and replacement after 7 – 10 days to clear the site of infection. Dr K is worried about the prospect of repeated episodes of non-viable Broviac lines however much care is taken to maintain the integrity of the line.
53. In relation to what continuation of life sustaining treatment would mean for C his view is that it would involve continuing care in much the same way as now including medical oversight (such as attention to new problems such as infection), nursing interventions (suction of tracheostomy, administration of drugs, hygiene cares, repositioning), therapist input (maintaining positioning and respiratory physiotherapy) and nutritional attention by dieticians. This care is not in Dr K's view and experience realistically deliverable outside critical care (Paediatric Intensive Care or should he become more stable in High Dependency) - C's acuity would certainly be too high to be managed safely on a standard ward even with expertise in Long Term Ventilation.
54. The benefit for C of continuing care is that it would include the preservation of life and give him the ongoing enjoyment that he derives from familial visiting. In both his written and his oral evidence Dr K was careful to acknowledge that C's parents do not agree what is the extent of that enjoyment. He readily agreed however that the WhatsApp recordings produced by the father show response and interaction.

55. It would also maintain the possibility for improvement however small such a possibility might be. Dr K's view as the paediatric intensivist in this case is that there is a negligible prospect of any meaningful improvement.
56. Dr K's opinion is that to withdraw life sustaining treatment would be in C's best interests and would allow him what he describes as a controlled, dignified and peaceful death. He explained in some detail the reasons which have led him to come to that conclusion and which may be summarised as follows:
- i) C has very abnormal peripheral neurology which has not demonstrated any improvement over very many months. The consensus is that he is unlikely to show any improvement
  - ii) He is completely dependent on ventilation and it is not envisaged that C will ever be liberated from invasive ventilation even if there were to be some improvement in other clinical aspects
  - iii) There is uncertainty around C's future ability to tolerate feed but at present he is completely dependent on intravenous nutrition which subjects him to additional burdens and risks
  - iv) C is subjected to unpleasant interventions - either intrinsically uncomfortable (such as suctioning) or ones that are ordinarily not distressing yet are experienced by C in such a way (such as basic nursing care) and that is not expected to improve.
  - v) C continues to be subjected to procedures to maintain his life including placement/replacement of venous access (including Broviac lines)
  - vi) C demonstrates suffering which Dr K describes as 'frequent'. Whether that suffering is due to pain, anxiety, distress or discomfort it is the Doctor's view that the medical and nursing teams are uniquely placed to observe the severity of it in providing as they do constant care.
  - vii) C's quality of life is poor. His distress and positioning difficulties mean that he is effectively bed bound. This differs from other children with significant medical problems who are able to be mobilised and interact with their environment.
  - viii) Although C at times seems to derive enjoyment from family interactions these are, in Dr K's view intermittent and limited. He did, however, accept that C's family spend longer uninterrupted periods with him and may be well placed to observe his responses and to interpret them. Albeit of course his mother and father observe and interpret them differently
  - ix) C's medical instability means that he is unable to leave the PICU - even if there is some improvement it is difficult to see C being able to be managed outside of Critical Care (including High Dependency which in this respect is akin to PICU) let alone a ward or even at home. This effectively means he is permanently distanced from loved ones. He is not, said Dr K, a boy with the prospect of going home.
  - x) C's health may continue to deteriorate in an unpredictable way, particularly around infection and consequences of his lack of muscle tone and positioning resulting in musculoskeletal complications (such as joint problems including deformation or stiffness)
  - xi) C is at risk of sudden deterioration which could result in his death without the presence of his family at this side
  - xii) It is difficult to know what C would want but his current clinical condition is far removed from his previous level of functioning and life aspirations

57. In the overarching consideration which he and his team had given to C's situation over many months, they collectively arrived at the point that there is no good outcome for him. He acknowledged that withdrawal of life sustaining treatment was in his view the 'least bad' outcome. No one within his wide multidisciplinary healthcare team had, he said, expressed a contrary opinion.
58. Dr K was asked in some detail about discussions at MDT meetings and in particular a meeting he had attended on 1<sup>st</sup> February 2023 at which there had been some discussion about the prospect of recovery of movement following a nerve conductivity result. Present at the meeting were Dr S from Neurology and her neurophysiology colleagues.
59. The meeting records the prognosis as '*guarded at best and poor at worst*' but there then appears following further discussion this: '*on further discussion guarded/good would be very limited recovery (5-10%) of axones which might be reflected in a flicker of movement. This is not certain and a clinically significant recovery seems extremely unlikely*'. From the context it is not possible to tell, and nor could Dr K who had been at the meeting say whether what was under discussion was 5 –10 % of axones in total or from the level at which C had axone recovery at the time of discussion. Dr K did not have minutes or a note of the meeting, but in his evidence though he could not recall from whom it came he spoke of one component of the discussion about recovery at that meeting including the possibility of being able to operate a joystick.
60. The MDT notes of that meeting were notable for 2 further aspects recorded about which Dr K was asked. First: *Dr S is still wondering whether repeating this study in a short time - 1-2 months might be worthwhile*. He could not help, unsurprisingly, with what had been in the thinking of Dr S in wondering that and the question was revisited with Dr M (as to which more later). The other recorded aspect read: '*There was also discussion that there may be some merit in assessing C's muscles with imaging as if there is fibrosis and fatty changes in the muscle then this may be a sign that this is irrecoverable*'.
61. That imaging appears to have been undertaken by the time that there was an MDT meeting on 8<sup>th</sup> March, at which Dr K was also present and about which he was also asked. By that meeting what is recorded is that: *There is evidence of atrophy of the muscles and some fatty deposition. There is also some dependent oedema in the pelvic muscles and possible inflammation/oedema*
62. Yet despite the seeming fear at the 1<sup>st</sup> February meeting that detection of fatty deposits might indicate irrecoverability, the notes continue:

*It is difficult to know what these findings suggest but is possible that it is an evolving process.*

*Very hard to know if this is reversible*

*There are scoring systems available but this is difficult since they are for other neuromuscular disorders*

*We discussed and agreed that a muscle biopsy is unlikely to add to the findings. We also agreed that rediscussing with Dr S would be sensible*

Unsurprisingly, Dr K did not feel able to add much to the neurological issues in the note as recorded save that the collective view as he saw it had not been that it was to be regarded as indicative of likely clinical recovery.

63. Dr M first met C on 21 March 2022 after he had been in PICU for some while, but his responsiveness and interaction had been observed markedly to have deteriorated. He has been involved in C's care since and taken part in best interests meetings and discussions. In terms of recovery, by May last year C has been able to open his eyes, turn his head to mid-line and show responses to questions by eye blinking, putting out his tongue or opening his mouth. Dr M was clear that recovery in those who do recover from polyneuropathic critical illness is slow, for him the lack of any significant steps to recovery during the last 12 months was a very discouraging indicator. Since neuropathy was so widespread here and there have been no steps to recovery he was doubtful that there would be meaningful recovery within say the next 3 months. Notwithstanding his caution, cross-examined by Mr Mant about the MDT records to which Dr K had been taken Dr M when asked by Mr Mant if there were to be a further EMG and clinical analysis and a consideration of the amount of independent breaths that would give more confidence either way as to prognosis, agreed that it would. He had previously expressed the view that the changes seen were not, or were not likely to be clinically significant.
64. Asked explicitly about the way in which Dr S had been wondering about the possibility repeating the study after a short period of months, whether that would not be a reasonable thing to allow that extra time to be more sure what is likely and what is the best case, Dr M again agreed that it would be a reasonable thing.
65. Dr P has had overall responsibility for C's gastroenteral care. It has been challenging and ultimately impossible to reinstate him on any form of enteral feeding successfully. He is currently reliant on TPN for all his nutritional requirements. Successive attempts to reintroduce enteral feeds have been unsuccessful. Further attempts could, she thought, be considered if the collective MDT felt appropriate and in conjunction with a clear plan for increasing or reducing depending on his symptoms. However, it has been difficult to find a suitable opportunity for restarting feeds due to C's baseline level of discomfort/distress, and the potential negative impact on his symptoms and quality of life that it would have. Furthermore, even if feeds are restarted, it is likely that C will continue to require TPN in the medium to long term based on his previous response to feeds. Notably that response has been characterised by the experience of very significant pain and discomfort.
66. Dr P's view remains that long term TPN is associated with damage to the liver, the risk is lessened if feeds into the GI tract can be added which has not been possible for C so far. For children to be discharged on TPN, the family needs to be trained to administer it at home and then a request is sent to NHS England to be approved. As it relies on tubes into the veins to provide TPN, there can arise issues with the lines blocking and needing to be replaced, if this occurs often then it can be difficult to identify new veins to be used. All of the above would only be possible if C was considered well enough to be discharged home. He is not of course a gastroenterology patient only and the wider clinical evidence of his condition means that discharge home is not an option.
67. It is this that has brought her to her view when considering his best interests which is expressed in these terms *C continues to have difficult symptoms to control and is not able to tolerate feeding into his bowel despite intensive input. Long term TPN will not improve his symptoms of distress/discomfort. He may be able to tolerate some feeding into his gut but, based on his recent toleration of feeds, this will not be sufficient to meet his requirements for fluid, nutrition or growth. It is likely that he will continue to remain reliant on TPN to meet his nutritional requirements which brings with it risks*



*of infection, damage to his liver and the potential need to replacement of his central lines used to deliver it.*

68. From Mr Q , respiratory physiotherapist, I heard graphic descriptions of the physiotherapy interventions carried out with C during the period that the goal towards which the team were working was rehabilitation. It is unnecessary to set out all of the detail but among the aspects that were striking from the evidence were:
- i) the time the process even of moving him into position takes and the number of people required to do so;
  - ii) the comparatively short period of time of the treatment before the lengthy and difficult process in reverse was undertaken to return C to bed;
  - iii) the burdens on C in terms of real pain throughout all of it,
69. Since he had no purposeful movements, it was necessary to use a tilt table with him. On other occasions a chair hoist was used to move him to a sitting position in an effort to improve posture. C found sitting unbearable. A bed bike had achieved no purpose. To be experiencing the discomfort and pain inevitable in physiotherapy were it working to a rehabilitative goal would be more readily justifiable than the clinical decision making committee found it to be when it met on 24<sup>th</sup> August. Having heard the evidence of Mr Q of what was entailed it can be understood why the decision to move away from the physiotherapy regime in place was made.
70. Physiotherapy in the sense of passive range of movement continues, Mr Q 's ultimate view to the court remained as he had expressed it in writing:

*I do not feel there are any other Physiotherapy treatment options available to C. Unfortunately, I think it is extremely unlikely he will recover any movement in his upper/lower limbs or trunk. I think it is highly unlikely he will recover enough spontaneous respiratory effort to progress on the ventilator.*

71. His view is that the only benefits for C of receiving Physiotherapy at present are to maintain the range of motion of his joints and his position in the bed as best that can be achieved, and to assess his ventilation and provide treatment if indicated. To attempt the previous regime would be to place a significant burden on C in the form of significant distress and worsening of his posture.
72. Charge nurse R was similarly bleak about the prospects for C's future. His evidence, however, illustrated how subjective a concept pain is not only for those experiencing it but also for those observing it. He did not agree when asked that his experience of C matched what appeared from the pain charts to be some days when there was little or even no pain. His own experience was of pain or discomfort a good deal of the time. He could not recall the last time he had seen C smile. In the earlier stages of his admission to PICU Mr R had seen C on a near daily basis. The fact that he is now in a more senior role with management responsibilities means that his contact though continuing is less. Though when I came to hear his mother's evidence she too made reference to the fact the infrequency of smiles and responses as time has continued.
73. I treated with some caution those parts of his statement where he gave opinions about C's up to date condition. I do not think for a moment that he was not giving a view that was genuine or that was in any sense intended to mislead but I was struck by the dissonance between what he had said in parts of his statement and the other evidence about C. By way of illustration this:

*Basic functions that were once there - such as communication - have now also diminished. C also no longer appears to be able to move his tongue nor his head.*

*There appear to be very minimal signs of understanding and interaction between C and nursing staff and/or parents. Having known and cared for C now for over a year, all aspects of his personality are absent. Sadly, C only seems able to express just one trait: distress*

74. The observation that C's communication has diminished chimes with other evidence – though no one can say with clarity why this is, but it is simply not the case that he can no longer move his tongue or his head. Nor did I recognise in the evidence of other non-family witnesses the description of one in whom all other aspects of his personality are absent and with an ability to express only distress. Mr R had to accept in cross examination that his description in this part of his statement was not reflective of the situation in which C now is albeit that the situation is very bad. I was left perplexed as to how it had come to be expressed in that way in his written evidence.
75. Dr L even in her experience as a palliative care expert where management of pain in seriously, often terminally, ill children is at the fore of her professional skill-set has found C's case uniquely challenging. She was unequivocal in her oral evidence that she was unhappy with both the frequency and the degree of episodes of breakthrough pain which remain a feature of his life.
76. She explained that it is not possible to assess C's current cognitive ability. C appears to be able to follow one step commands such as stick out your tongue. C is inconsistent when asked to follow two step commands such as, stick your tongue out then blow a kiss. Asked if she agreed that the videoclips of responses to his family showed more than that, she was unconvinced. There are significant restrictions in what assessments can be undertaken due to C's limited movements and limited communication. He responds to people's voices using head movement and facial expressions. His level of understanding cannot be assessed, and it is difficult to know whether he is understanding the content of a conversation or responding to familiar and/or animated voices. Expanding on this it might be that C, who is of course not a toddler, may be interacting with loved ones in the way a toddler might and what he is responding to is familiar voice, modulations and tone. Mr Mant, whilst reminding her that the father's experience is of interaction at a higher level than that, asked Dr L whether she would not agree that even the 'toddler' interactions she thought these might be are a valuable and meaningful human interaction and she readily accepted that they are.
77. Her own assessment of his communication responses is that they are inconsistent and unreliable at times as observed and assessed by her over multiple interactions. This is corroborated by the therapist assessments as well as outside formal sessions by nursing staff that care for C. Understanding the reasons why can only be assumed but therapists have considered mood, distractions, fatiguability, impact of medications and motivation. In this respect she was unable to assist in her oral evidence with whether what she perceives as a diminution in his responsiveness is an inability to respond or a decision not to – i.e. can't or won't. She used to be far more confident in knowing what he had understood and what he was communicating – a clear example she gave was of him rolling his eyes up to the right which was an indication of displeasure/boredom/disinterest with whatever he was being asked. She had not seen that latterly. Though it seemed on the recordings that some others working with him had seen something similar.
78. Dr L although cross examined at length in relation to what the most objective measure of pain i.e. that which comes from the pain scores, remained of the view that C's pain was neither well managed nor diminishing and was unwilling to accept on the basis of

a seeming improvement as between February and March this year that that was so. The picture in her view is far more complex. Her overall and considered opinion remained as expressed in her written evidence:

- i) C has a life-limiting condition.
  - ii) C's ability to communicate appears to be static and there has been no discernible improvement in recent months.
  - iii) C is not considered to have the competence to be involved in decision-making regarding whether to continue or withdraw life-sustaining treatment and will never likely develop this capacity.
  - iv) C has an ongoing need for symptom management. Attempts to wean off symptom control medications have caused worsening adverse symptoms. In her opinion, he will continue to need both background medications (around the clock) and breakthrough medications (as and when needed) for the rest of his life. Many medications can only be given intravenously to be effective due to his gut problems.
  - v) Control of adverse symptoms is unlikely to improve further, and he will continue to have significant periods of distressing adverse symptoms. Interventions to address these symptoms involve using medications with unwanted side effects including sedation, worse gut function, dysphoria, and blood pressure instability. The severity of C's condition and the restriction of living life in a PICU in a hospital leads Dr L to what she says is the 'devastating conclusion' that it is impossible for C to derive sufficient benefit from continued life.
  - vi) The balance of benefits and burdens (as to which Dr L has appended a benefits and burdens balance sheet to her report) mean that his current life is intolerable, this will not improve and so life-sustaining treatment in the form of ventilation should be stopped, and he should be allowed to die.
79. All of those medical professionals who have given evidence before me have done so with a sincerity and an anxious concern for C which has been striking. It is reflective of the way in which they have looked after him for so long.

## The Legal Framework

### The General Approach To Children's Serious Medical Treatment Cases

80. As a child, C who is not Gillick competent, can neither consent to nor refuse medical treatment. The Court of Appeal in *Re A (A Child)* [2016] EWCA 759; [2016] All ER (D) 183 said the following (§31), with reference to Lady Hale's judgment in *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591:

“Whilst its application requires sensitivity and care of the highest order, the law relating to applications to withdraw life sustaining treatment is now clear and well established. It can be summed up with economy by reference to two paragraphs from the speech of Baroness Hale in what is generally regarded as the leading case on the topic, notwithstanding that it related to an adult, against the backdrop of the Mental Capacity Act 2005. In *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67; [2014] AC 591 Baroness Hale said at paragraph 22:-

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

And from paragraph 39:-

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

81. In Manchester University NHS Foundation Trust v Fixsler and others [2021] EWHC 1426; [2021] 4 WLR 95 (§56) it was held that:

“The court may grant a declaration declaring that treatment in accordance with the recommendation of the child's doctors can take place, on the grounds that it is in the child's best interests (see Re B (A Minor) (Wardship: Medical Treatment) (1982) 3 FLR 117). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement between those with parental responsibility for the child and those treating the child (An NHS Trust v MB [2006] EWHC 507 (Fam)). The court has no power to require doctors to carry out a medical procedure against their own professional judgment.”

82. At para [57] of Fixsler MacDonald J summarised the applicable principles in relation to medical treatment of non-Gillick competent children, where there is disagreement as proposed treatment by those with parental responsibility. These are clearly relevant to me as I consider C’s situation :

“The following key principles can be drawn from the authorities, in particular In Re J (A Minor)(Wardship: Medical Treatment) [1991] Fam 33, R (Burke) v The General Medical Council [2005] EWCA 1003, An NHS Trust v MB [2006] 2 FLR 319, Wyatt v Portsmouth NHS Trust [2006] 1 FLR 554, Kirklees Council v RE and others [2015] 1 FLR 1316 and Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410:

i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.

- ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be.
- iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled: “This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism.”
- iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests
- v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.
- vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
- vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.
- viii) Each case is fact specific and will turn entirely on the facts of the particular case.
- ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:
- “The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient

and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.” “The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.”

83. In *Barts Health NHS Trust v Dance & Ors (Re Archie Battersbee)* [2022] EWFC 80 Hayden J noted the strong presumption in favour of life but also considered the concept of human dignity in the context of a child's best interests:

36. In *North London Clinical Commissioning Group v GU* (supra), I observed the following: ... ..

- i. Firstly, human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;
- ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;
- iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;
- iv. thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;
- v. the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;
- vi. compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry."

38. Archie's rights, protected by the European Convention on Human Rights, are engaged. In the present context, the relevant rights are established by Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for a private and family life). As the ECtHR recognised in *Burke v UK* [2006] (App 19807/06), [2006] ECHR 1212: "the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (see also its findings as to the compatibility of domestic law with Article 2 in *Glass v. the United Kingdom*, no. 61827/00§ 75ECHR 2004-II)."

41. These sentiments were re-stated in *An NHS Trust v Y* [2018] UKSC 46 at [92], Lady Black delivering the judgment of the court stated: "Permeating the determination of the issue that arises in this case must be a full recognition of the

value of human life, and of the respect in which it must be held. No life is to be relinquished easily."

84. Poole J in *Guy's and St Thomas' Children's NHS Foundation Trust v Knight and another* [2021] EWHC 25 (Fam), once again considered where in the best interests analysis the views of a child's parents fall. His caution as to the distinction to be borne in mind between parental views and child's best interests is one, I have held in my mind as I have listened to the strength with which C's mother and father have explained to me their entirely genuine but completely different views about what is best for their son:

"98. I accept that the views of a parent on what is in the best interests of their child should be given due respect and taken into account, but that does not mean that those views should avoid proper scrutiny, let alone that they should be determinative ... There is a distinction between the views of a parent as to their child's best interests or their child's own wishes, and the independent wishes of the parent. ... I do take into account the judgment of the ECtHR in *Gard and others v UK* (above) to the effect that compliance with Art 2 of the European Convention on Human Rights does require the decision-maker to take into account the wishes of those close to the child when determining the child's best interests, perhaps all the more so in the case of a young child whose own wishes cannot be ascertained. I also bear in mind that Ms Parfitt has an Article 8 right to family life which ought to be considered. If so, parental wishes are not "wholly irrelevant". Nevertheless, an objective assessment of a child's best interests should not be confused with the satisfaction of a parent's wishes, even if the wish to care for a child at home is wholly understandable.

#### Religious And Cultural Issues

85. When I consider the strong albeit rebuttable presumption in favour of life I bear in mind that the fact that C's life is now much diminished, it is still a life which adds to the extended family of which he is a much-loved member. See : *Barts Health NHS Trust v Raqeeb and others* [2019] EWHC 2530 (Fam); [2020] 1 FLR 1298 at §169:

"... The sanctity of life is a fundamental, indeed sacred, principle from which there flows a strong presumption in favour of a course of action that will prolong life. Within this context, Tafida's life has inherent value. It is also of value to Tafida herself, it is precious to her parents, sibling and family and even now it adds, in whatever small and incomplete way, to the body of collective human experience. Tafida is profoundly disabled but a life of disability is of equal value to all other lives."

86. Religious faith has a place in C's life and in my decision and so in making decisions for him the religious and cultural context of those decisions are informed (though not determined) by the values of his family: see *Fixsler and others @ [70]- [71]*.

#### Professional Guidance

87. This case is one in which those charged with making decisions medically for C have had regard to the *RCPCH Guidance*. The Royal College of Paediatrics and Child Healthcare published the document, "Withholding and Withdrawing Life Saving Treatment in Children" in 1997. In 2015 revised guidance was published under the title, "Making decisions to limit treatment in life-limiting and life-threatening

conditions in children: a framework for practice.” It has been considered by the President of the Family Division in *Re Jake (A Child) [2015] EWHC 2442 (Fam)*, MacDonald J in *Raqeeb* and Poole J in *Pippa*. I have had it firmly in mind as I come to think about decisions for C.

It is prefaced as follows:

“We emphasise two important points so as to avoid confusion:

This document sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible—NOT circumstances under which such treatment *must* certainly be withheld or withdrawn.

The document describes situations in which individual children should be spared inappropriate invasive procedures— NOT *types* of children to whom appropriate procedures should be denied.”

There are three sets of circumstances in which the RCPCH advises that treatment limitation can be considered “*because it is no longer in the child’s best interests to continue, because treatments cannot provide overall benefit*”.

I:- When life is limited in quantity If treatment is unable or unlikely to prolong life significantly it may not be in the child’s best interests to provide it.

These comprise:

Brain stem death, as determined by agreed professional criteria appropriately applied

Imminent death, where physiological deterioration is occurring irrespective of treatment

Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit

II:- When life is limited in quality This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits

Burdens of the child’s underlying condition. Here the severity and impact of the child’s underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life

Lack of ability to benefit; the severity of the child’s condition is such that it is difficult or impossible for them to derive benefit from continued life.

III:- Informed competent refusal of treatment.

Adults, who have the capacity to make their own decisions, have the right to refuse LST and to have that refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of



LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no ethical obligation to provide LST

### Discussion

88. A feature which makes this case particularly difficult is C's level of awareness. Ms Scott for the Guardian in her closing submissions described it as '*the factor of magnetic importance*' in the case. Neither I, nor counsel, have identified in any of the leading authorities an instance where a decision of this sort fell to be made in respect of a child whose consciousness was at the level which C has. Specifically, Dr K in his oral evidence said that C does respond. He went on to observe '*that makes this more difficult*'.
89. I had watched carefully several times before starting this hearing the WhatsApp videos exhibited by the father to his statement. Since the hearing I have watched carefully those sent in by agreement following the conclusion of submissions. There is a danger in overreliance, or over interpretation, of such recordings, whether that is by someone who very much loves C and risks seeing what they want to see, or by a Judge whose viewing of them is from a clinically uninformed perspective. To me it appeared that C was smiling and/or responding by raising an eyebrow to questions asked about his sister and so I asked Dr K if I should understand what I was seeing as something more than a reflex response. His evidence was that within the context of those clips what was being seen was that *he is responding and on two of the videos obviously responding with a smile*. Accordingly, whilst I caution myself about overreliance on the video evidence, I proceed on the basis that it is safe to regard those clips as showing what they appear to show at face value of C in the seconds or minutes to which they relate. I bear in mind also of course that they show only one aspect of his experience and not those aspects of his life described by others of pain, discomfort and distress.
90. Within the contexts of any consideration of the 'burdens' of C's life falls pain. There is good evidence that he experiences pain. Dr L in her evidence explained that it had not been possible to manage that pain as effectively as she would wish. Her oral evidence was that he is on a complex mixture of pain relief medications including intravenous morphine yet is often assessed as experiencing mild or moderate pain. Sometimes the assessment is that he is experiencing severe pain. By comparison with pain management in other children, of which she has wide experience because of her particular specialism, Dr L does not think his pain is acceptable.
91. The recording of pain is by reference to scales either numerically 0–10 or by 'faces' or by crying. Most often it is the numerical recording that is used. Aspects of that have been the focus of attention in the cross examination and exploration of evidence at this hearing. These have included but are not limited to the following:
- i) The recordings even allowing for the framework of the score by FLAC imports an element of subjectivity to it
  - ii) A recording is to a degree a 'snapshot' of when it is taken
  - iii) There appeared in some instances to be what might be regarded as an over recording of pain in the sense that if there was no pain a zero score was not always included and so the number of recordings in a 24 hour period was fewer than should be seen
  - iv) The full run of pain recordings was not available and so it was not possible to see whether over a period of months there was a gradual trajectory of

improvement or deterioration.

- v) There was not consensus as to whether what was recorded as less pain represented a meaningful improvement or was a reflection of stronger or different pain relief such as opiates
92. Of those aspects it was perhaps the lack of complete recordings that presented the greatest difficulty. Mr Mant's submission that on what has been disclosed what emerges is that March 2023 shows fewer recordings of severe pain than was recorded in February is one I accept. I accept also the submission that there is overall more pain than had been shown in November, but the absence of the intervening months, and the question of how that should be interpreted when the absent notional 'zeros' are added in makes it impossible to say what that means if anything by way of progress or deterioration. Medication records for January show that there is medication prescribed for pain on about half the days. This does not match the written evidence on which the Trust relies that it was needed on average 'every day or so'. The fact that at this hearing not only parents but also professional witnesses have described to me how their own subjective impression or interpretation differs from the recordings underscores the need for as clear an objective picture as possible.
93. At this hearing there has been a focus not only on pain and discomfort but also of distress. There are occasions also when C has been described as being withdrawn or showing what has been described as 'pervasive sadness' and this has led to him being prescribed medication with an anti-depressant component. There are also recorded instances when he is noted to be exhibiting 'distress' which is not objectively associated with pain or discomfort from handling or interventions or from obvious gastric pain (such as the Guardian's report records witnessing) but which appears to be distress. I of course accept the submission made on behalf of the father that I must not speculate on the cause of his emotional distress. In closing submissions Mr Brownhill drew attention to the fact that Nurse R thought he might be *scared or missing his family*. that is exactly the sort of speculation to be avoided. To the extent that the Trust relies in oral submissions by counsel on the evidence of Mr R that C had, at the time he was still able to make movements, made a movement that might be interpreted as seeking to shield his body from view during intimate care. I do not regard that as one it is safe to weigh in the balance (not least because it was not a recording identified for me in the records). I similarly apply caution to the views expressed by some that he had seemed to them to flush with embarrassment when intimate care tasks are undertaken. It would be too easy to read into those subjective observations.
94. I take a different approach to the observations when C is observed simply to be in distress. Those occasions when for example he is recorded crying. I am satisfied that it is more likely than not that there are occasions when, though not in pain he is in acute distress. It is a feature associated with his level of awareness to which I have already referred. I accept Mr Mant's submission that I should not speculate as to the cause of his distress, but I do not see that that prevents me from finding that, whatever its precise cause or causes when seen, that it is there. Nor do I regard it as impermissible to consider the fact that there are episodes of distress when I consider what attitude this young person might have of his situation now. *Re H [2022] EWFC 14*
95. When this matter came before me following the issue of the application by the Trust, there had not been the recent changes of the nerve conductivity study and the reported respiratory efforts. Recognising that those had taken place the Trust obtained a short update from Dr Varma before the start of the hearing and within the hearing from Dr

N. Mr Mant's complaint that second opinion Drs were not called and there was no opportunity to cross examine them is one that is solidly met by the riposte that they were not asked for but his better point is that those short updating reports are not ones which address the best-case scenario or the possibility of recovery so far as reinnervation may translate to clinical terms. That is a submission made within the context that even by the time it was being made there had still not been disclosure of full neurology notes and MDT meeting.

96. Each of the very eminent specialists from whom I have heard at this hearing has given evidence of how very unusual C's case is. All accepted the description of the development of his overall clinical picture and his current polyneuropathy as 'unique'. Dr M did not seem to me to regard the polyneuropathy in the context of critical illness as so very unusual but agreed that the development of C's condition and the combination of his presentations made it an exceptionally difficult case.
97. There was consensus that as a starting point to enable me to go on and determine a best interests analysis I should determine a factual matrix. Ms Scott in her final submissions itemised those aspects as to which the Guardian invites factual findings:
- a) C has some degree of awareness, albeit his level of cognition is unknown.
  - b) C experiences frequent episodes of pain, discomfort and distress.
  - c) C experiences periods of comfort and/or pleasure.
  - d) C has some ability to communicate, albeit this is inconsistent.
  - e) The prospects of C making any meaningful recovery are very low.
  - f) The prospects of C ever being well enough to leave ICU are very low
98. As to a) to d) it is possible on the evidence before me to reach some conclusions. In the light of my overarching conclusions in the case however I do not think it right to reach final conclusions on those aspects now. As to e and f, I am not satisfied that it is safe to reach conclusions on the basis of the evidence before me.
99. Whilst Mr Mant has made very persuasive submissions that I should declare that it is in C's best interests to continue to receive life-sustaining treatment, having regard to the strong presumption in favour of taking all steps necessary to maintain life, and holding in my mind that presumption as I consider the evidence available as to C's level of consciousness and the fact that for reasons which appear elsewhere in this judgment it has not been possible to ascertain his present wishes and feelings, I do not at this hearing as a final position accept that submission.
100. Nor however has the Trust, even with the support of Ms Scott for the Guardian satisfied me that it has established its case for a declaration that it is not in his best interest to continue to receive life sustaining treatment and so in his interests to make the declarations as expressed by Mr Brownhill in his closing submissions.
101. I am satisfied that in this very unusual case although I am at this stage unpersuaded by his primary position, I should accede to Mr Mant's secondary submission. In opening Mr Brownhill for the trust took the position on any adjournment for further evidence that:
- a) This case is distinct from the circumstances which obtained in *A(A Child) (Withdrawal of Treatment: Legal Representation [2022] EWCA Civ 1221*

- b) The application is made too late since the Father has been aware for at least 6 weeks since the Trust filed its position statement and made oral submissions at the first hearing as to its position and provision made in the order
- c) Any application must be balanced against C's continuing pain and distress (as to which reliance was placed in particular on the evidence of Mr R)
102. This was modified following the evidence to one whereby it is submitted to the Trust that the experts proposed are not obligated by law and that the requirements set out in *Gard* do not require them having regard to Article 2. I accept that I am not obligated to direct the experts sought.
103. Even though not obligated however I note that independent experts were instructed in all of the recent leading cases concerning the withdrawal of life sustaining treatment in children (none of whom had C's level of awareness) see: *Evans v Alder Hey Childrens NHS Foundation Trust* [2018] EWCA Civ 984 ; *Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin) ; *Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust* [2021] EWCA Civ 362; *Manchester University NHS Foundation Trust v Fixxler* [2021] EWCA Civ 1018 ; *Barts Health NHS Trust v Dance* [2022] EWCA Civ 935). Within this context, Mr Mant makes the powerful submission that where, as here, there is a dispute it would be appropriate, and the court would usually expect to have the benefit of independent expert evidence.
104. Matters which are critical to a best interests decision are in my judgment properly to be considered by an independent expert from the field of intensive care . I accept the submission that such is required to provide independent medical scrutiny of the overarching position notably as to medical prognosis and life expectancy in circumstances where at this hearing when Dr K was asked by the mother whether in reality C is dying, his position was that he was being kept alive by PICU but is not actively dying. He was not able to say what might be his life expectancy, though he had a clear view as to his very poor quality of life. There are furthermore within the overall picture of instability which would not at the moment permit his care to be stepped down even from PICU to HDU, aspects of his presentation which are stable or managed – the integrity of his skin; the hypertension and the TPN arrangements for nutrition delivery and so there might be reason to think that if stability could be improved in other aspects these would not militate against stepping down his care from ICU.
105. In modifying the position, as I see it, rightly, on the application to adjourn for further expert evidence, Mr Brownhill did not return to the submission that it was 'too late'. The father obtained representation something like a week before the final hearing. Furthermore, the Trust and the Guardian in ways which does each significant credit agreed that in the event that I were to conclude that it is necessary that that further experts should be instructed as sought by the father, they would together fund that work as a joint instruction. I will return later to why that approach would be necessary.
106. The Guardian accepts that the application for further expert evidence has its roots in the need for the court to give the utmost scrutiny to the case. She draws my attention, rightly, to the fact that over the course of three days of evidence I have heard seven Trust witnesses giving evidence and subject to cross examination. She is of course right about that, as she is about the fact that thousands of pages of medical records have been produced.
107. She relies on the evidence of Dr K who she characterises as representing in effect the totality of the views of the treating team from one of the best centres of excellence

in the country when he expresses the view that before C could be released from PICU

- i) His physiological signs would need to be stable
- ii) He would have no longer to need ‘masses of interventions’
- iii) The Ventilation requirement would need to move from delivering variable pressure to constantly delivering a pressure

108. The clear view of Dr K is that he is a long way from that. In her attractive and well-pitched oral submissions, Ms Scott submitted that there is no requirement that I should have evidence from another PICU consultant or any other independent expert. What ultimately resolves the question of whether there should be an adjournment for further expert evidence is if I conclude that I need it before making a final decision.

109. I accept that per *An NHS Trust v X* [2005] EWCA Civ 1145. I must be satisfied to “high degree of probability” that withdrawal of life sustaining treatment is in C’s best interests and that this reflects the level of scrutiny required and approach to best interests judgment.

110. Mr Mant submits that it is routine in these very serious cases for Trusts to obtain second opinions from consultant paediatric intensivists and neurologists before proceedings are issued see: *Battersbee* [2022] EWCA Civ 935 at [13]. Here although there were second opinions obtained from neurologists there has never been a second opinion or any other review from an intensivist or PICU consultant. I interpreted the submission that it is ‘routine’ as permitting of the contemplation that there may be cases in which as Mr Brownhill put it in opening the clinical situation of the child concerned outweighs the procedural rights of the party putting their case, but I have not concluded that this is the situation here.

111. The greatest hesitation for me in reaching the conclusion that I should direct an adjournment for further expert evidence is that the effect of doing so is that C is kept in pain, discomfort and distress while that is done. In fact by the conclusion of this hearing one of the matters which became the subject of the greatest dispute was the extent to which he continues to experience severe episodes of pain. It would be tempting in making the decision to permit further evidence to lean on the fact that, to the extent that I have an objective picture of pain it is that the most recent month is better than that which came before. I know however that those whose expertise lies in pain management have not accepted that and I also know that on occasion little or no apparent pain may be only reflective of increased opiates. It is therefore a more honest approach to the decision, to take it knowing that C is likely to continue to experience pain in the intervening period. I recognise also that the precarious state of the Broviac line – to the extent that ceilings of care have had to be agreed or determined in a range of forms – means that there is scope for that pain to increase. It is not speculation for me to say that it is informed by up-to-date evidence

112. On balance, even when I consider that aspect for C if I permit an adjournment, and given what lies in the other side of that balance if I do not, I have determined that it is right to accede to the application for further expert evidence from a paediatric intensivist/PICU consultant.

113. Since the field of neurology is the only field in which there has been before proceedings started a second opinion sought, I had wondered whether the better course than permitting another might be to invite those who had given that second opinion the opportunity to give a more considered and detailed report. This to address the uncertainty which has emerged from neurologists at this hearing as to what the 5 – 10 % recovery in terms of axonal reinnervation means and to how most especially in the light of Dr K’s ‘joystick’ evidence (from the MDT meeting) that might translate if at all into clinical recovery and the wider neurological prognostication. Should it be

the case that it is impossible to find within a tolerable timescale someone with sufficient expertise to undertake the task then that may yet be the route to further and more detailed second opinion evidence. In the first instance, however I will give the opportunity for an independent expert to be identified.

114. I will therefore adjourn the applications for declarations pending the instruction of experts in
- i) PICU
  - ii) Neurology

I am aware that preliminary enquiries were being made during the hearing and will invite Counsel to agree a draft order with directions reflecting my decision. For reasons that are obvious the shortest possible reporting time should be sought from any expert.

115. Earlier in this judgment I made reference to the fact that the Trust and the Guardian has each indicated that in circumstances where, contrary to the position they each advanced on the point by I were to accede to the Father's application to adjourn and permit independent expert evidence to be obtained, they would fund that work on a joint instruction basis. That comes about in the following way. In respect of the applications before me C's mother and father are not eligible for non-means non-merit tested funding. C's mother does not oppose the Trust's application and so might be thought to be less in need of representation. C's father, who does not agree with the application made, has been represented pro bono by Mr Mant with conspicuous skill, ability and a professional generosity that has been unstinting. It was obvious, however, that were I to accept his case on independent expert evidence there would be no source of funding for it.
116. The father, I was told had been offered funding in this case by an organisation or organisations but on terms which he was not prepared to accept it. I did not ask, and was not told, any more about that. I was however told, in respect of my enquiries as to the family's approach to the issue of reporting restrictions that the father as well as the mother wished to avoid the prospect of what was described as a 'media circus' which sometimes has attended similar tragic cases even though he realised that publicity might assist him with the funding position.
117. It is in those circumstances that the Trust and the Guardian have taken the view they have in respect of funding. It is very much to the benefit of everyone – most of all C – that the father has not found himself having to revisit decisions about where he might look for funding.
118. Had these parents found themselves before the Court because, within public law care proceedings the Court was to be asked to make a decision which might result in the removal of their child from their care for the remainder of his childhood they would have been able to be represented had they wished it. In circumstances where the Court is asked to make a decision which might result in their child's life coming to an end they are not. In this and other cases I have tried to understand how that can be so. The understanding eludes me.