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Neutral Citation Number: [2018] EWCA Civ 550

Case No: B4/2018/0441

IN THE COURT OF APPEAL (CIVIL DIVISION)
ON APPEAL FROM
THE HIGH COURT OF JUSTICE
FAMILY DIVISION
Mr Justice Hayden
[\[2018\] EWHC 308 \(Fam\)](#)

The Royal Courts of Justice
Strand, London, WC2A 2LL
6 March 2018

Before:

LADY JUSTICE KING
LORD JUSTICE MCFARLANE
LORD JUSTICE MCCOMBE

Between:
E (A Child)

Applicant

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(Official Shorthand Writers to the Court)

Mr Stephen Knafler QC, Mr Leon Glenister and Ms Sophy Miles (instructed by MSB Solicitors)
appeared on behalf of the Appellants
Mr Michael Mylonas QC (instructed by Hill Dickinson) appeared on behalf of the First Respondent
Ms Sophia Roper (instructed by CAF/CASS Legal) appeared on behalf of the Second Respondent

LADY JUSTICE KING:

1. This is an application for permission to appeal, with an appeal to follow if granted, from an order made by Haynes J sitting in Liverpool on 20 February 2018. By his order the judge made a raft of declarations, in particular that Alder Hey Children's NHS Foundation Trust ("the Trust") would be acting lawfully and in the best interests of a little boy, Alfie, now 21 months old (born 9 May 2016), by withholding certain medical treatment including all forms of ventilation and that thereafter he receive only palliative care.
2. The effect of the declaration would be that the ventilator which keeps Alfie alive would be removed and he would die shortly thereafter. The parents, who chose to be unrepresented before the judge, seek to appeal the declarations and accompanying orders. They now have the benefit of leading counsel, Mr Knafler QC, and junior counsel to represent them in relation to their application for permission to appeal.
3. The Trust and Alfie's Children's Guardian, each support the judge's decision and submit that the challenge to the judge's order by the applicant is misconceived.
4. Before embarking upon what is necessarily a somewhat lengthy and detailed judgment in the light of the legal issues raised by Mr Knafler, I think in fairness to the parents waiting anxiously on the other end of a telephone line, I should tell them immediately that their applications for permission to appeal are refused, save in one respect, and insofar as permission to appeal is granted in that respect, the appeal will be dismissed.

The facts

5. Alfie was born on 9 May 2016. The judge described his early days as follows:

"3. Alfie was born at the Liverpool Women's Hospital. He was delivered at full term with a healthy weight and discharged home three days after the birth. Alfie's mother was then 18 years old and this was her first pregnancy. Alfie's father, Tom, was 19 years of age. Though self-evidently very young and though Alfie had not been planned, his parents were delighted by him. They were both determined to be good parents and, from what I have seen and read, were instinctive and natural. The couple were well supported by their respective extended families. Alfie was a happy, smiling baby, who seemed to be perfectly well."
6. This attractive snapshot of a young couple embarking on parenthood was, tragically, destined to be short lived.
7. The first indications that there were problems began to manifest themselves in July 2016, and by the time Alfie was six months of age there were significant signs of developmental delay. Alfie was referred to the Outpatient Clinic at the Alder Hey Hospital in November 2016. Alder Hey is a tertiary referral centre and one of the country's leading centres for the assessment and treatment of children suffering from neurodegenerative disorders. The unit has a team of 12 consultant paediatric intensivists and 6 paediatric neurologists, together with a complement of specialist paediatric nursing staff.
8. Upon examination at referral, it was clear that Alfie, now six months old, was functioning in a range appropriate to a six- to eight-week-old baby. A brain scan was carried out and flagged up abnormalities, including, the possible diagnosis of a mitochondrial disorder. Two weeks later, on 14 December 2016, Alfie was admitted to Alder Hey Accident and Emergency Department with a high fever and seizures. An initial plan to admit Alfie into the High Dependency Unit for non-invasive respiratory support was abandoned when his condition deteriorated significantly, and instead he was transferred to the paediatric Intensive Care Unit.

9. Throughout December and January Alfie was very unwell with severe bilateral pneumonia, such that the treating clinicians felt that they had no alternative but to broach with the parents the real possibility that Alfie might not survive. In the event, Alfie did not succumb to the pneumonia. The judge found Alfie's survival became an "absolutely crucial feature of Alfie's treatment in the father's mind." He went on;

"I think, having prepared himself for the worst, he believes that Alfie's triumph over this infection is indicative of potential for more general recovery. In cross-examination the father has been critical of the doctors for having the conversation with him which he believes to have been premature. He perceives this as "the hospital giving up on Alfie"."

10. One can well understand the father's position, particularly given that there was, and remains no diagnosis. In his mind, with a diagnosis would come the possibility of treatment and, if not a cure, at least a possibility of halting the inexorable deterioration which was the only alternative.

11. Whilst Alfie recovered from pneumonia, his EEG and clinical presentation were grim. An EEG in January 2017 showed attenuation, with little in the way of reactive response for much of the time. Changes were seen on the trace only when Alfie had a seizure. Clinically, he showed no response to tactile, visual, auditory or sensory stimulation. Now, a year on, his papillary response is entirely abnormal, with only the most subtle brief dilation to light, without any normal constriction.

MRIs

12. As already noted, the MRI performed on 30 November 2017 raised the possibility of either degenerative disorder or a metabolic disorder. A second scan was undertaken in February 2017 and a third on 22 August 2017. This third scan, shockingly, revealed that by now 70% of Alfie's brain had been destroyed.

13. Given that by the time the matter came before the judge the most recent scan was nearly six months old, the judge, first having been reassured that it would not be either unsettling or intrusive for Alfie, requested an up-to-date scan. A further scan was therefore undertaken on 2 February 2018. This scan showed the almost total destruction of Alfie's brain, with fluid identical to water or CSF now present where brain matter should be.

14. The Trust instructed Professor Helen Cross, the Prince of Wales Chair of Child Epilepsy at UCL and Great Ormond Street Institute of Child Health, to conduct an independent clinical review of Alfie. Professor Cross reviewed the EEGs and the MRIs and examined Alfie at the PICU.

15. Professor Cross concluded that Alfie has a progressive, ultimately fatal, neurodegenerative condition, most likely a mitochondrial disorder. Professor Cross considered all the evidence, including the dramatic deterioration on the EEG. Professor Cross concluded that Alfie's brain was now only able to generate seizures, in other words his seizures are not contributing to the neurological degeneration but are a consequence of it.

16. The judge recorded the way in which Professor Cross, in evidence, explained the situation to the father when she was cross-examined by him in the hearing:

"During her cross-examination by F she told him in gentle terms that even if it were possible to stop Alfie's seizure, which did not look likely given his poor response to anticonvulsant treatment to date, his brain is entirely beyond recovery. The brain, she said, again on F's enquiry, simply has no capacity to regenerate itself, unlike, e.g. the liver. She agreed that nobody knew quite why the brain does not have the ability to do so, but is simply "acknowledged by neurologists that it cannot.""

17. The professor explained in response to one of the father's questions that the brain can only generate further from existing matter, and therefore there is no possibility that because Alfie's brain has not yet at his age become fully formed, it might generate as opposed to regenerate, brain matter.

18. Professor Cross' sombre conclusion was that, "even if Alfie is able to sustain respiration in the short term, on discontinuing ventilation his respiratory effort will not sustain life." Further therapy, she said, would not have an impact on the seizures and even if the seizures were reduced it would not change Alfie's outcome.
19. In August 2017, in the light of the latest MRI, the Trust had discussions with the father proposing that treatment of Alfie should be limited, including the marking of his notes with "Do Not Resuscitate." While initially agreeing to this, the parents subsequently withdrew that agreement. In the light of this impasse, at a meeting on 25 August 2017 the parents were asked to provide the clinicians at Alder Hey with a list of those specialists that they would wish Alder Hey to contact with a view to requesting them, or some of them, to conduct further independent reviews of Alfie. Dr M contacted the doctors on the parents' list, doctors who live and work variously in the United States, Germany, and the United Kingdom. Of those approached, Dr Samuels, a consultant respiratory paediatrician, was the only one who had the necessary expertise and was willing to review Alfie. This he did, at the parents' request, on 30 August 2017.
20. Dr Samuels agreed with the diagnosis of the Alder Hey team, and with the futility of treatment. He noted, however, the parents' inability to accept his advice and recommendations as to withdrawal of treatment.
21. On 6 September 2017 a firm of Italian lawyers, instructed by the family, requested that a clinical team from Ospedale Pediatrico Bambino Gesù in Rome assess Alfie. Three specialists from Bambino Gesù in Rome reviewed Alfie's records and on 11 September 2017 travelled to Alder Hey to examine him. They too agreed that Alfie had a neurodegenerative disease and fitting disorder which was untreatable. They agreed that even if further testing were carried out, it would not provide a cure or, "bring a different treatment plan." Nowhere in their report was it suggested that it would be in Alfie's best interests for ventilation to be continued. Bambino Gesù were, however, prepared to treat Alfie at their hospital in Rome. Unfortunately it was not until 27 October 2017, six weeks later, that the Bambino Gesù report was disclosed to the Trust. In the body of the report Bambino Gesù said in respect of the proposal that Alfie be transferred to their care:
- "It is possible that during travel Alfie may present continuous seizures due to stimulations related to the transportation and flight: these seizures might induce further damage to (the) brain, being the whole procedure of transportation at risk."
22. Notwithstanding the reports of both Dr Samuels and the Bambino Gesù team, further attempts at mediation between the Trust and the family in November 2017 did not result in agreement. In those circumstances, some 13 months after his referral to the hospital, on 5 December 2017 Alder Hey issued an application in the High Court. In her witness statement in support of the application Dr M noted that Bambino Gesù were not offering any additional investigations or new therapies and described the inherent risks in transferring ventilated patients. Dr R said:
- "Should Alfie's condition significantly deteriorate during this transfer that there is risk of a sudden and "undignified" death outside the secure environment of a paediatric intensive care unit with his family present.
- Transferring any terminally ill patient to another hospital either within the UK or abroad for continuation of treatment which we deem to be of no benefit to the patient is not something that we have ever considered as appropriate for patients on the paediatric intensive care at Alder Hey. As treating doctors we cannot in good conscience agree that by simply transferring Alfie to another hospital (to continue prolonged treatment which is of no benefit to Alfie) that we are acting first and foremost in Alfie's best interests. Sadly in Alfie's case, the futility of his situation is not changed by transferring him to the Bambino Gesù hospital. In my opinion the proposed transfer will be of no benefit to Alfie and is not in his best interests."
23. On 11 December 2017, a few days after the Trust had issued their application, a Dr Matthias Hubner, the medical director of an organisation in Germany called Paediatric Air Ambulance which provides paediatric intensive care transports for critically ill and injured children, went to the Alder Hey

hospital posing as a friend of the family. He deliberately withheld his professional status from the doctors and staff, and examined Alfie without the knowledge and agreement of the hospital. He neither reviewed the medical notes nor discussed Alfie's case with the clinical team. Dr Hubner produced a so-called "fit to fly" certificate in December, but it was only during the course of the proceedings in February that a report materialised that he had previously written and sent directly to the father's then lawyers.

24. Dr Hubner's statement began with an assertion that he had seen all of Alfie's files, whereas in reality he had seen very little. As the judge put it, "most alarmingly" Dr Hubner's travel plan for Alfie suggested the use of anticonvulsant medication which, on the basis of Alder Hey's experience with Alfie, would have been both ineffective and inappropriate. It is clear from the statement, and very properly accepted by Mr Knafler during the course of argument, that much of that statement is predicated on a complete misunderstanding of the seriousness of Alfie's condition; by way of example only, Dr Hubner calculates a Glasgow Coma Scale which is clearly wrong and attributes responsiveness in Alfie and reflexes from him which had lain dormant for many months, and which inaccurate information must have been based upon information that can only have come from the parents, who have been unable to accept that what movements they see in Alfie are not positive responses by him to them. In cross-examination Dr Hubner told Mr Mylonas on behalf of the NHS Trust that he had not in fact used the air ambulance in cases where patients were dying.
25. In his statement Dr Hubner said, "In my professional opinion the transfer does not present any particular difficulties, and Alfie **Evans** is fit to travel." Little wonder, then, that the judge not only found that Dr Hubner's evidence suggesting that Alfie could be simply transferred by air abroad could not be relied upon, but rather the judge said:

"I am at a loss to know quite why Dr Hubner fell so far below the standards expected of his profession. I am constrained to say that he has failed the parents, the Court but most importantly, Alfie."
26. On the back of Dr Hubner's "fit to fly" certificate the father's solicitors wrote to Alder Hey Children's Hospital. Mr Knafler explained to the court that the solicitors did not themselves draft the letter in question, rather it had been drafted by a legally-trained "supporter" of Alfie, and similarly that the covert attendance at the hospital had been arranged by others and not by the solicitors.
27. The letter of 14 December sent to Alder Hey Children's Hospital enclosed a copy of the "fit to fly" certificate and indicated that Alfie was to be removed from the hospital forthwith. The letter before claim in judicial review proceedings was attached to cover the situation in the event that Alder Hey refused to facilitate Alfie's departure. The letter before claim contains a quite extraordinary statement that were Alder Hey to remove mechanical ventilation, it would "constitute the offence of murder or alternatively an offence of manslaughter." In my view the letter in its entirety was wholly inappropriate and should not have been written.
28. Upon the advice, or recommendation, of the same unknown supporter, an application was next made for a report prepared by Professor Nikolaus Haas, Medical Director of the Department of Paediatric Cardiology and Paediatric Intensive Care at the University Hospital in Munich. Alder Hey cooperated fully with the preparation of Professor Hass' report. Professor Hass too shared the view of Alder Hey as to the prognosis in relation to Alfie. He too agreed that no further tests were appropriate or necessary. He did, however, recommend that a tracheostomy and gastrostomy be fitted, which would potentially allow home ventilation for the "short rest of his life."
29. The overall medical opinion then was ad idem, namely that Alfie suffers from an untreatable neurodegenerative condition from which he will die.
30. Given that the vast majority of the white matter of the brain, and a significant degree of the cortex have been wiped out by what the judge described as the "remorseless degenerative condition", it is no surprise that Alfie is deeply comatose and that for all intents and purposes is unaware of his surroundings. He is entirely dependent on a ventilator, is fed by a nasojunal tube, is likely to be blind and have a severe hearing impediment even if he is not entirely deaf. He will never make any developmental progress.

31. The father believed, and continues to believe, that Alfie responds to him. Professor Haas helpfully dealt with this in his report, saying:

"The main underlying problem seems in my opinion that from the side of Alfie's parents that they do not understand and/or accept that:

a. the majority of Alfie's reaction to external stimuli (i.e. touching, pain stimulation like pinching, etc., reaction to noise, parents voice etc.) is very likely not a purposeful reaction but very likely caused by seizures (as proven by repeat EEG monitoring)

b. these reactions are very difficult to separate especially for parents. Based on videos shown to me, there may however well be a change in Alfie's behaviour and his status may well fluctuate

c. the seizure activity is very likely the consequence of the underlying process

d. the neurodegenerative process has unfortunately progressed so far that an improvement or recovery is also extremely unlikely."

32. Professor Hass' view, then, ties in with that held by the other experts and the treating physicians. The Bambino Gesù team described Alfie as being in "a semi-vegetative state" and Professor Cross said Alfie's brain can now "only generate seizures."

33. Dr Samuels explained that light and sound can produce physiological changes in Alfie and suggested three possible explanations, those explanations being basic reflex, seizure-related activity, or discomfort on his part. Dr Samuels did not consider they were meaningful responses. His view is also at one with Dr R, who said that [29]:

"Alfie does not show any response other than seizures to tactile, visual or auditory stimulation. He does not show any spontaneous movements. His motor responses are either of an epileptic nature or spinal reflexes. He is deeply comatose and for all intents and purposes unaware of his surroundings."

34. The judge, at the request of the father, watched a number of videos he had made which he said demonstrated Alfie responding to him. The judge in his judgment said at 57 :

"57...At the conclusion of his evidence F produced a considerable number of video clips. The overwhelming majority of these demonstrated the accuracy of the medical view in that they illustrate reactive responses which were frequently intentionally generated by F. I stress that this was entirely well-motivated on F's part. In simple terms touching part of Alfie's body generates a predictable response in a different muscle group. There were two videos however which caused me much thought. In one Alfie appears to emit a lusty yawn in another he appears actively to withdraw from a touch to his mouth. I have watched these, as F is aware, repeatedly and carefully. "

The judge went on at 58:

"58. Following the videos being produced Dr R also viewed them extensively and thoughtfully. The following day, having had time to reflect overnight, Dr R was recalled to the witness box. He told me that for the yawn to be a true, as opposed to a reflexive action, it would require a complex response of the brain. In simple terms, Dr R said there is not sufficient of Alfie's brain left intact for this to occur, other than as a reflexive action. The effect is entirely to mimic a purposeful yawn. I completely understand why F has invested so much in it. When the yawn occurs F's response is one of obvious delight. However, it is impossible to avoid the force of Dr R's conclusion, it has to be confronted. The second video can far more easily be seen as reflexive. I accept this evidence not merely because of the careful, interpretative expertise of Dr R but also because it unifies the remaining evidence, the EEG's, the scans, the observations of Alfie over many months

by so many medical professions and indeed, the preponderance of the parents' own observations."

35. Dr R believes it to be "highly unlikely" that Alfie has any awareness of pain or discomfort and he shows none of the recognised signs that would suggest this to be the case, such as an increase in heart rate and blood pressure or respiratory rate, or to respond to uncomfortable or painful stimuli. However, as Alfie is unable to communicate Dr R sounds this note of caution:

"It is important to consider whether, despite his inability to respond, Alfie may still have some awareness of pain and discomfort and this should therefore be kept to an absolute minimum, considering that he might still be able to "feel" uncomfortable sensations. I think it unlikely that Alfie has any ability to be reassured by the voices and touch of his parents."

36. On 20 January 2018 Alfie was visited by his father, who brought with him two women one of whom was Dr Jankowska, a Polish doctor with a speciality in paediatric oncology, also, it is understood, introduced to the family by the "supporter". Whilst there was no subsequent application to adduce evidence from Dr Jankowska, the nurse who was present at the time identified himself and introduced himself to Dr Jankowska, who did not respond by identifying herself or say that she was either medically trained or that she was there to perform a review on behalf of the parents. This was therefore the second clandestine review which took place on the Paediatric Intensive Care Unit.

37. It was and is the father's wish that Alfie should be permitted to travel to the Bambino Gesù Hospital in Rome, and if necessary be thereafter transferred on to Professor Haas' Munich hospital. The father is passionate in his views, and through Mr Knafler he told the court that although he would not wish Alfie to die being transported to Italy, he would rather that happened than ventilation being withdrawn. He wanted, he said, to fight on with "Alfie's army." Alfie, he says, would be "fighting", continuing to explore options and fighting the battle which would lead, he believes, to an "heroic death" as compared to a managed death in a hospital.

38. The father understandably, and as was conceded by Mr Knafler, really has no clear plan. On one level he understands that neither Bambino Gesù nor Professor Haas in Munich are offering Alfie any hope for the future. The most they are offering is surgery in the form of a tracheostomy and gastrostomy, which would allow the possibility of his being ventilated at home, but that is not what the parents are asking for. It is clear and understandable that they have been unable to think through the disadvantages for them as a family to relocating either to Italy or Munich without the support of their extended families and unable to speak either language, in order to be able to spend Alfie's last weeks or months in what they currently regard as a more empathetic environment. Mr Knafler was unable to help the court to understand why the father's proposal involved Alfie being transferred to both Italy and Munich.

39. Professor Haas has, however, a very different view from the UK clinicians and the guidance on which they rely in relation to the withdrawal of treatment, and it is to that which the father clings.

40. Professor Haas said, in what was regarded by the judge to be "inflammatory and inappropriate" terms, (not least because "the views expressed bear no relationship and do not engage with the facts of this case"):

"Because of our history in Germany, we have learned that there are some things you just don't do with severely handicapped children. A society must be prepared to look after these severely handicapped children and not decide that life support has to be withdrawn against the will of the parents if there is any uncertainty of the feelings of the child, as in this case."

41. Professor Haas relies upon the now-discredited evidence of Dr Hubner, who referred to Professor Haas as "his boss". Therefore proposed that Alfie could be transported "safely around the world at any place without any major risks for him." The professor proposed therefore that Alfie would be transferred to his hospital where he would spend 14 days in their Paediatric Intensive Care Unit where a tracheostomy and peg insertion would be carried out. There would be EEG monitoring and a further

MRI of his brain. The parents, he said, would be trained to manage a home ventilation system and, notwithstanding his express view that no useful tests could be performed to improve Alfie's condition there would, he said, be neuro-paediatric assessment and potentially additional genetic testing. The cost, he said, would be €65,000 for the 14 days, including surgery but excluding the cost of the air ambulance and transport.

42. The judge set the views of Professor Haas as to the withdrawal of treatment against the tenets of the Roman Catholic faith, which is the faith of the parents, saying:

"I have, on the parents' behalf, taken very great care to evaluate the quality of Alfie's present circumstances, even though I accept entirely the conclusion of the medical evidence that treatment for Alfie is futile. It does not follow axiomatically that the futility of Alfie's situation leads to the immediate withdrawal of ventilation. Life itself has an intrinsic value, however, tenuous or vestigial its hold. I am very much aware that both parents are Roman Catholics, brought up in that tradition. They do not present themselves as devout or observant but it is obvious to me that their faith plays a part in their life and sustains them both at this very difficult time. In his closing remarks F said that Alfie is "our child and a child of God". It is important that these beliefs are considered within the broad gamut of relevant factors to which I have eluded and which cumulatively illuminate where Alfie's best interests lie."

43. The judge went on to set out in full an open letter from His Holiness Pope Francis sent to the president of the Pontifical Academy for Life, dated November 2017. It is not necessary to set out that open letter to any great extent, save to include two brief references:

""Consequently, it is morally licit not to decide not to adopt therapeutic measures, or to discontinue them, when their use does not meet that ethical and humanistic standard that would later be called "due proportion in the use of remedies"

... It is clear that not adopting, or else suspending, disproportionate measures, means avoiding over-zealous treatment; from an ethical standpoint, it is completely different from euthanasia, which is always wrong, in that the intent of euthanasia is to end life and cause death. Needless to say, in the face of critical situations and in clinical practice, the factors that come into play are often difficult to evaluate. To determine whether a clinically appropriate medical intervention is actually proportionate, the mechanical application of a general rule is not sufficient. There needs to be careful discernment of the moral object, the attending circumstances and the intentions of those involved. In caring for and accompanying a given patient, the personal and relational elements in his or her life and death, which is after all, the last moment in life, must be given a consideration benefitting human dignity."

44. The judge regarded His Holiness' open letter as "a comprehensive answer to the tendentious views expressed by Professor Haas." I agree with the judge. In my judgment there is nothing in the personal views as expressed by Professor Haas which, all other things being equal, could or should impact upon the proper application of a best interests' evaluation.

The judge's conclusions

45. The judge, having set out and analysed the evidence, described the legal backdrop and relevant guidance against which he would reach his conclusions. I set them out in full, as, in four short paragraphs, the judge correctly states the law and outlines the relevant guidance as it currently stands. It is therefore unnecessary for me to elaborate by reference to either earlier or additional authorities, of which there are many:

"46. It is necessary here to root my own conclusions in the framework of the Law and within the available guidance. The Royal College of Paediatrics and Child Health has produced guidance, published March 2015: **Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A Framework for Practice**'. The following is relevant:"

The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide 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:

C.. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.....In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation.

47. The legal framework is now relatively easy to state though always difficult to apply in applications as sensitive and fact specific as this. I do not consider that an exegesis of the applicable Law is required here, indeed the risk is that to do so might eclipse the lode star which guides the Court's approach i.e. "the best interests of the child".

48. The test is perhaps best encapsulated by Baroness Hale in **Aintree University Hospital NHS Trust v James** [\[2013\] UKSC 67](#), namely:

"[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." ...

"[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."

49. In **Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust** [\[2017\] EWCA Civ 410](#), McFarlane LJ observed:

"As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail

and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

46. The judge, whilst rejecting the evidence of Dr Hubner, did not exclude the possibility that travel by air ambulance could be a theoretical option. It required, however, to be considered in the context of Alfie's present condition and in particular that it was unsafe to discount the possibility that Alfie experiences pain, particularly surrounding his convulsions. Given that whilst the evidence pointing to this would be unlikely, it cannot be excluded.
47. The judge identified the obvious challenges to transporting Alfie, initially to Italy and possibly thereafter to Munich. He noted that away from intensive care, Alfie would be more vulnerable to infection and the maintenance of his anti-convulsive regime, (already of limited effect) risked being further compromised by the travel. The journey, the judge said, "self-evidently, will be burdensome." The judge rightly faced up to the worst of all possible outcomes, saying, "Nobody would wish Alfie to die in transit." The judge even then did not rule this out as an option, considering the potential present risk, and saying in terms that the risk "might be worth taking" if there were any prospect of treatment, but there is none. It was that that the judge found irreconcilable with Alfie's best interests. The judge therefore held that "All this drives me reluctantly and sadly to one clear conclusion. Properly analysed, Alfie's need now is for good quality palliative care."
48. The judge concluded:

"66. It was entirely right that every reasonable option should be explored for Alfie. I am now confident that this has occurred. The continued provision of ventilation, in circumstances which I am persuaded is futile, now compromises Alfie's future dignity and fails to respect his autonomy. I am satisfied that continued ventilatory support is no longer in Alfie's best interest. This decision I appreciate will be devastating news to Alfie's parents and family."

The Grounds of Appeal

49. Mr Knafler seeks permission to appeal the order of the judge on three grounds which can be summarised as follows:

Ground One: Failure properly to weigh parental views in the best interests decision and consequential breach of Article 14 ECHR (read with Article 8) and Article 8 ECHR.

Ground Two: Failure properly to consider what would be an appropriate palliative care pathway, and more widely, how the consequences of the judgment were to be managed.

Ground Three: Failure to assess matters relevant to best interests or weigh up the available alternatives.

50. It quickly became apparent that Grounds 2 and 3 were of little weight, and the focus of the proposed appeal was and is in relation to ground 1 and in particular:

"Ground 1(3) (b) the readiness of the court to override parental choice under its inherent jurisdiction, in the absence of proof of *significant harm*, is incompatible with Article 14 ECHR (read with Article 8)."

51. In those circumstances I will deal briefly with Grounds 2 and 3 prior to moving on to consideration of the Article 14 (inaudible).

Ground 2

52. Ground 2 has in effect not been pursued by Mr Knafler. The father (and no doubt the mother) is anxious to have adequate time to understand, consider and contribute to any end of life plan for Alfie. The Trust has indicated that they are happy to respect the father's wishes in this regard and will not, following the dismissal of any appeal, act with unseemly haste. The Trust gave the court that assurance

against their continuing concern that this desperate father will do anything to put off the day when ventilation will be withdrawn. Clearly if no compromise or agreement can be reached, the matter will have to be returned to the judge for him to hear argument and to fix a date.

Ground 3

53. Ground 3 particularises the alleged failure as follows:

"The learned judge should have weighed the alternative care plans in assessing what was in Alfie's best interest. To properly assess the parental plan required him to make conclusions as to (i) whether Alfie suffers pain; (ii) whether it is safe to transport Alfie away from Alder Hey; and (iii) whether it was in Alfie's best interest to undergo a tracheostomy or gastrostomy."

54. In my judgment this ground has no reasonable prospect of success, and permission to appeal has been refused.

55. Put shortly,:

i) The Trust and Dr Samuels each expressed the opinion that it was uncertain whether Alfie suffered discomfort or not. Professor Haas agreed that he did not know whether Alfie experienced pain or not. Given the evidence the judge was entitled to conclude as he did that it was "unsafe to discount the possibility that Alfie continues to experience pain" [60].

ii) In relation to the proposed air transport of Alfie to Italy, this was dealt with in written and oral evidence and in the judgment. The judge concluded [45] that the evidence of Dr Hubner could not safely be relied upon. The judge was entitled to take into account the views of Dr Samuels, Dr M and the Bambino Gesù experts all of whom shared the view that Alfie could suffer increased seizures in transit which have the potential to cause further brain damage, together with the evidence as to the possibility of Alfie experiencing pain and discomfort. The judge additionally set out the inherent risks to Alfie of travel outside the hospital.

iii) In relation to the tracheostomy and gastrostomy which the parents sought, it was common ground that the provision of either or both could not in any way impact upon the fundamental fact that Alfie's condition is "catastrophic and untreatable" [19]. Dr M's evidence was that, if Alfie was able to feel pain, provision of either surgical procedure would cause further discomfort. The judge did not however close his mind to the parents' proposals taking the view that notwithstanding the risks had there been any prospect of treatment it may yet have been worth subjecting Alfie to the journey [64].

56. The judge considered all the evidence presented to him and concluded that it was not in Alfie's best interests to receive continued ventilator support. Given that conclusion, provision of the tracheostomy and gastrostomy as well as the transfer to another country could not possibly be in Alfie's best interests.

Ground 1

57. Turning then to Ground 1. Prior to addressing this proposed ground of appeal I wish to deal briefly with Mr Knafler's submission that the judge failed adequately to take into account the parents' views. Mr Knafler submitted that those views should have been carefully assessed and given appropriate weight. The judge, he submitted, had failed to highlight this in his self-direction found between paragraphs [47] and [50] of the judgment. Had he taken those views into account, Mr Knafler said, the judge would have focused more on the safety of the proposed air transport and sought additional evidence in that respect (Dr Hubner having been discredited) had he done so, he would have allowed the parents to "prepare their best vision" of taking Alfie to Italy and then Munich.

58. In my judgment such an allegation is not only without substance, but grossly unfair to a judge who could not have done more to ensure that the father and mother had every opportunity of expressing their views and of having them taken into consideration. The submission does not sit comfortably with the opening remarks made by Mr Knafler to the effect that the judge's judgment was a "humane

judgment" reached with "great professionalism in fraught circumstances" and "the judge made a real effort to see the parents' point of view." In this respect Mr Knafler referred the court to the judge's judgment at paragraph 54, where he had described in gentle and empathetic terms his visit to Alder Hey to see Alfie. The judge in that paragraph was complimentary and insightful in relation to the parents, complimenting them on their devotion to Alfie whilst also recognising the exemplary care Alfie receives from the medical team in the PICU.

59. Ms Roper, on behalf of Alfie, recognised the fact that simply because a judge is empathetic it does not necessarily mean that in conducting a best interests evaluation he properly took into account all those matters which he should. Mr Mylonas, therefore, highlighted a number of matters in addition to the judge's gentle, considerate approach to the parents' views found throughout the judgment.

- The case was listed for two days but ran for seven days as the judge assisted the father, who had chosen to represent himself, in putting forward his case.
- It was by the judge's efforts that Dr Hubner, who it was anticipated would give supportive evidence, attended court. At the judge's behest the court staff also spent several days trying to contact Professor Haas, who was returning from an international conference, as he had not been warned to attend to give evidence by the father. A telephone link was arranged, although at the last minute the father decided he did not wish to challenge Professor Haas' evidence.
- The judge arranged for a further MRI scan to be carried out during the proceedings, and also recalled Dr R to respond to the videos of Alfie that the father had produced.
- The judge factored in with care the dilemma in which the father found himself, setting out the father's plan insofar as he had formulated it, namely that if no solution should be found upon transfer to the Munich hospital, only then should Alfie be allowed home to die "when he decides to."
- It should also be noted that it is common ground that the father on occasion during the course of the trial lost control. The judge, all agreed, responded to what could only have been extreme provocation with calmness, patience and courtesy, and in doing so kept the trial on track and ensured that Alfie's interest remained the focus of the hearing.

60. In *Gard*, MacFarlane LJ said this in relation to the importance of parental views:

"112. It goes without saying that in many cases, all other things being equal, the views of the parents will be respected and are likely to be determinative. Very many cases involving children with these tragic conditions never come to court because a way forward is agreed as a result of mutual respect between the family members and the hospital, but it is well recognised that parents in the appalling position that these and other parents can find themselves may lose their objectivity and be willing to "try anything", even if, when viewed objectively, their preferred option is not in a child's best interests. As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."

61. In my judgment, to all intents and purposes the whole focus of the judge's judgment was on the parents' views. They could not have been given greater respect than that which they were given by this judge. Had that not been the case then, given the unanimous view of all the doctors as to Alfie's prognosis, the decision to withdraw medical treatment could have been made comfortably within a day rather than the seven days which this judge properly devoted to the case.

The welfare principle at Article 14, European Convention on Human Rights

62. Mr Knafler accepts that as far as the law currently stands, the only test properly applied by the court when considering an application under the inherent jurisdiction, whether in relation to serious medical treatment or otherwise, is the best interests of the child. I admit to being less than wholly clear whether he says the "significant harm" test he seeks to import should apply to each and every application under the inherent jurisdiction, or whether his case is that the extreme nature of an application for the withdrawal of treatment of a child necessitates a separate approach and the application of what he would say is a more rigorous test before the wishes of the parents can be undermined by way of court order.
63. The question of whether a "significant harm" test should govern proceedings of this type was considered by the Court of Appeal and thereafter by the Supreme Court in its permission to appeal judgment, and finally in Strasbourg, in the well-known *Charlie Gard* case.
64. Baroness Hale it might thought had laid such a proposition to rest. She said *In the matter of Charlie Gard*, 8 June 2017:
 - "4. The legal test which he applied was whether further treatment would be in Charlie's best interests and in his order he expressly found that it would not be."
 5. The parents argue that this is not the right legal test. In this sort of case the hospital can only interfere in the decision taken by the parents if the child is otherwise likely to suffer significant harm. But that apart, it is argued, decisions taken by parents who agree with one another are non-justiciable. Parents and parents alone are the judges of their child's best interests. Any other approach would be an unjustifiable interference with their status as parents and their rights under Article 8 of the European Convention on Human Rights. But there are several answers to this argument.
 6. Firstly, applications such as this are provided for by statute: the Children Act of 1989. There was an application for a specific issue order in this case, as well as under the inherent jurisdiction of the High Court. Both are governed by the same principles. Section 1, sub-section 1 of the Children Act 1989 provides that the welfare of the child shall be the paramount consideration in any question concerning the upbringing of the child in any proceedings. This provision reflects but is stronger than Article 3.1 of the United Nations Convention on the Rights of the Child, which says that in any official action concerning the child, the child's best interests shall be a primary consideration.
 7. Furthermore, where there is a significant dispute about a child's best interests the child himself must have an independent voice in that dispute. It cannot be left to the parents alone. This has happened in this case because Charlie has been represented by a guardian.
 8. The guardian has investigated the case in his best interests and the guardian agrees with the hospital and with the judge's decision.
 9. So, parents are not entitled to insist upon treatment by anyone which is not in their child's best interests. Furthermore, although a child can only be compulsorily removed from home if he is likely to suffer significant harm, the significant harm requirement does not apply to hospitals asking for guidance as to what treatment is and is not in the best interests of their patients. As the Court of Appeal found, it is in any event likely that Charlie will suffer significant harm if his present suffering is prolonged without any realistic prospect of improvement. This was found by reference to the judge's conclusions on the evidence.
 10. Finally, the European Court of Human Rights has firmly stated that in any judicial decision where the rights under Article 8 of the parents and the child are at stake, the

child's rights must be the paramount consideration. If there is any conflict between them the child's interests must prevail."

65. The European Court of Human Rights considered the matter some days later. In finding the parents' application to be inadmissible, the court reminded itself that:

"108. The Court has also reiterated that there is broad consensus – including in international law- in support of the idea that in all decisions concerning children, their best interests must be paramount (see *X v. Latvia* [59 EHRR 3](#) at [96]."

66. The court considered the submissions of the parents that the proper test was not one of "best interests" but one of risk of "significant harm" to the child [118]saying:

"118....that there is broad consensus – including in international law- in support of the idea that in all decisions concerning children, their best interests must be paramount. But the facts of the present case are exceptional (*the Court not having examples in its case law which addresses the approach to be taken in resolving such conflicts [107]*) and there is therefore a lack of guidance in the Court's case law on this point.)"

67. The ECHR went on to say that even had the test been one of significant harm there had been a finding that there was a risk of "significant harm", and that in any event the legal framework in place was "appropriate" [123] and in such cases the margin of appreciation was wide.

68. Mr Knafler accepts, as he must, that the course proposed by the hospital does not infringe either Article 2, Deprivation of Life, or Article 8, Respect for Family Life, both of which complaints were described by the ECHR as "manifesting ill-founded" in *Gard*. Rather he says that the courts in the *Gard* case did not have before them a submission that the making of a declaration for the withdrawal of medical treatment against the wishes of the parents under the inherent jurisdiction is discriminatory under Article 14 of the Human Rights Act 1998. Had he done so, he submits, they would have concluded that Charlie's parents had been the subject of discrimination for which there is no justification.

69. Mr Knafler goes on to submit that had the judge applied the proper test, significant harm, his decision may well have been different and the child's interests would have been found to have been subservient to the wishes of the parents, absent a finding of significant harm attributable to their care. The outcome, he submits, would have been that the parents would have been entitled to arrange for the removal of Alfie from Alder Hey Hospital, notwithstanding any view whether held by the Trust, independent experts or the court, that such a course would be inimical to his best interests.

70. This may be thought to have been somewhat of a bold submission, given the ECHR's recent reiteration of the supremacy of the child's best interests, and further than that as the ECHR had held in *Gard* at paragraph 124 so too I find that the court at first instance in this case was "meticulous and thorough... heard high-quality expert evidence, and accorded weight to all the arguments raised."

71. Having said that, Mr Knafler is right in his submission that no court has, to date, examined the issue through the prism of discrimination.

72. Article 14 says

"Prohibition of discrimination

The enjoyment of the rights and freedoms set forth in this Convention shall be secured without discrimination on any ground such as sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status."

73. The ground of discrimination relied on by Mr Knafler is that of "other status". In *Cameron Mathieson, a deceased child (by his father Craig Mathieson) v Secretary of State for Work and Pensions (Mathieson)* [2014] EWCA Civ 286; [2015] UKSC 47 [23] it was held that the child in question as a

"severely disabled child in need of lengthy in-patient treatment" had a "status case" falling within the grounds of discrimination prohibited by Article 14. Lord Wilson in his judgment put it this way at [23]:

"23...Why should discrimination (if such it be) between disabled persons with different needs engage article 14 any less than discrimination between a disabled person and an able-bodied person?"

74. It is accordingly accepted by Mr Mylonas and Ms Roper on behalf of the Children's Guardian (albeit somewhat reluctantly) that in no circumstance Alfie equally has the necessary status to fall within Article 14, as do the applicants by virtue of being his parents.
75. Having established status, Mr Knafler's core submission is that parents in the position of these parents are treated differently depending on whether the application is made under care proceedings (significant harm) or the inherent jurisdiction (best interests). There is no justification for that difference, Mr Knafler says, as each is ultimately doing the same thing, that is to say intervening in the life of the family in order to safeguard or promote the welfare of the child in a manner inconsistent with what the parents are doing or propose to do. It follows, he says, that there is no proportionate justification for the different approach to overriding parental choices under the inherent jurisdiction as compared with care proceedings under the Children Act 1991.
76. In *R v The Secretary of State for Work and Pensions ex parte Carson* [2005] UKHL 37, [2006] 1 AC 173 (*Carson*), the House of Lords considered the proper approach to a discrimination claim under Article 14. Lord Nicholls encapsulated the formulation of the relevant issues in one succinct paragraph:

"3. For my part, in company with all your Lordships, I prefer to keep formulation of the relevant issues in these cases as simple and non-technical as possible. Article 14 does not apply unless the alleged discrimination is in connection with a Convention right and on a ground stated in article 14. If this prerequisite is satisfied, the essential question for the court is whether the alleged discrimination, that is, the difference in treatment of which complaint is made, can withstand scrutiny. Sometime the answer to this question will be plain. There may be such an obvious, relevant difference between the claimant and those with whom he seeks to compare himself that their situations cannot be regarded as analogous. Sometimes, where the position is not so clear, a different approach is called for. Then the court's scrutiny may best be directed at considering whether the differentiation has a legitimate aim and whether the means chosen to achieve the aim is appropriate and not disproportionate in its adverse impact."

Lord Hoffman said in relation to the issue of 'relevant difference':

"14. There is no doubt that Ms Carson is being treated differently from a pensioner who has the same contribution record but lives in the United Kingdom or a treaty country. But that is not enough to amount to discrimination. Discrimination means a failure to treat like cases alike. There is obviously no discrimination when the cases are relevantly different. Indeed, it may be a breach of article 14 not to recognise the difference: see *Thlimmenos v Greece* (2001) 31 EHRR 15. There is discrimination only if the cases are not sufficiently different to justify the difference in treatment. The Strasbourg court sometimes expresses this by saying that the two cases must be in an "analogous situation": see *Van der Musselle v Belgium* (1984) 6 EHRR 163, 179-180, para 46.

15. Whether cases are sufficiently different is partly a matter of values and partly a question of rationality....."

And at 31:

"31...There is a single question: is there enough of a relevant difference between X and Y to justify different treatment."

And Lord Rodger:

"43.....As the speeches show, a court faced with a case of alleged discrimination should not go mechanically through a series of questions. Rather, it should look at the facts of the case as a whole and identify the particular issue or issues which will have to be resolved in order to decide whether there has been discrimination contrary to article 14.

44. Often, the critical question will be whether the person complaining of discrimination is really in an analogous situation to that of the person who is treated more favourably....."

77. The House of Lords judgments therefore marked the end to the more formulaic approach to Article 14, known as the *Michalak questions*, which had been formulated by Brooke LJ in *Wandsworth LBC v Michalak* [2003] 1 WLR 617.

78. *Carson* was subsequently considered in Strasbourg, in *Carson and Others v United Kingdom*, application number 42184/05, [51 EHRR 13](#), which confirmed the approach of Lord Nicholls.

"A. The Court's general approach"

61. The Court has established in its case-law that only differences in treatment based on an identifiable characteristic, or "status", are capable of amounting to discrimination within the meaning of Article 14 (*Kjeldsen, Busk Madsen and Pedersen*, [ECLI:CE:ECHR:1976:1207JUD000509571](#), cited above, § 56). Moreover, in order for an issue to arise under Article 14 there must be a difference in the treatment of persons in analogous, or relevantly similar, situations (*D.H. and Others v. the Czech Republic* [GC], no. 57325/00, [\(2008\) 47 EHRR 3](#), § 175, ECHR 2007; *Burden v. the United Kingdom* [GC], no. 13378/05, [\(2008\) 47 EHRR 38](#), § 60, ECHR 2008-). Such a difference of treatment is discriminatory if it has no objective and reasonable justification; in other words, if it does not pursue a legitimate aim or if there is not a reasonable relationship of proportionality between the means employed and the aim sought to be realised. The Contracting State enjoys a margin of appreciation in assessing whether and to what extent differences in otherwise similar situations justify a different treatment (*Burden*, cited above, § 60). The scope of this margin will vary according to the circumstances, the subject-matter and the background. A wide margin is usually allowed to the State under the Convention when it comes to general measures of economic or social strategy. Because of their direct knowledge of their society and its needs, the national authorities are in principle better placed than the international judge to appreciate what is in the public interest on social or economic grounds, and the Court will generally respect the legislature's policy choice unless it is "manifestly without reasonable foundation" (*Stec and Others v. the United Kingdom*, [GC], nos. 65731/01 and 65900/01, [\(2006\) 43 EHRR 47](#), § 52, ECHR 2006).

79. The task then for the court is to determine whether the parents and Alfie really are in an analogous or relevantly similar situation. If so, is the difference in treatment discriminatory? That is to say, is there objective and reasonable justification, or put another way, is it proportionate and does it pursue a legitimate aim? The court did consider whether there is in fact discrimination in breach of Article 14 will enjoy a wide, although not unlimited, margin of appreciation.

Are the proceedings under the inherent jurisdiction analogous with those under care proceedings?

80. Mr Knafler has to satisfy the court that these parents are in an analogous position to parents faced with State intervention in care proceedings. As a backdrop to deciding whether, as submitted by Mr Knafler, the situation is analogous as between a seriously ill child in care proceedings and a seriously ill child in declaratory proceedings under the inherent jurisdiction, it is helpful to look in a little detail at the comparators upon which Mr Knafler relies and at one on which he does not rely.

81. Part IV of the Children Act 1989 (CA 1989) carries the title 'Care and Supervision'. Under section 31.1 the court may on the application of a local authority make a care or supervision order.

82. Section 31 CA 1989 provides:

"(2) A court may only make a care order or supervision order if it is satisfied—

(a) that the child concerned is suffering, or is likely to suffer, significant harm; and

(b) that the harm, or likelihood of harm, is attributable to—

(i) the care given to the child, or likely to be given to him if the order were not made, not being what it would be reasonable to expect a parent to give to him; or

(ii) the child's being beyond parental control."

83. Section 31(9) defines 'harm' as "ill-treatment or the impairment of health or development including, for example, impairment suffered from seeing or hearing the ill-treatment of another." The component parts of that definition are further defined as follows:

"development" means physical, intellectual, emotional, social or behavioural development;

"health" means physical or mental health; and

"ill-treatment" includes sexual abuse and forms of ill-treatment which are not physical.

84. The definition is deliberately widely drawn. Section 31 provides the principal route for child protection in England and Wales and must, insofar as it can be achieved, be capable of capturing all forms of child abuse. Crucially, however, it comes into play in care proceedings only when a child is "suffering, or likely to suffer, significant harm" which is attributable to the care given to the child "not being what it would be reasonable to expect a parent to give to him." (or the child being beyond parental control). Mr Knafler submits that the requirement of the satisfaction of the threshold criteria is a source of discrimination, as the existence of that threshold means that parents are treated more favourably in care proceedings than under the inherent jurisdiction, when the court can interfere with their exercise of parental responsibility, notwithstanding that their child has not suffered significant harm.

85. The class of parents to whom this part of the Children Act 1989 applies are those parents in respect of whom there has been a finding by the court (or an admission by the parent(s)), of their having ill-treated or caused the impairment of health or development of their child, (or to have put their child at risk of such harm.) Only then, the "threshold" having been satisfied, can the court make either a care order or supervision order. Which (if either) of those orders is made is determined by conventional best interest evaluation carried out by the court. Further, the court can only make either a care order or a supervision order having approved a care plan put before the court by the local authority. The care plan is not a creation of the judge.

86. Section 33(3)(b) CA 1989 provides that :

"3) While a care order is in force with respect to a child, the local authority designated by the order shall—

(a) have parental responsibility for the child; and

(b) have the power (subject to the following provisions of this section) to determine the extent to which

(i) a parent, guardian or special guardian of the child; or

(ii) a person who by virtue of section 4A has parental responsibility for the child

may meet his parental responsibility for him.

87. On any view it would be seem inappropriate for a local authority to use s33(3)(b) CA 1989 (giving as it does power to a local authority to overrule the way in which the parents exercise their parental responsibility following the making of a care order) as a means to override the wishes of the parents by consenting to the withdrawal of treatment in circumstances where the parents wish to oppose such a course. As Ms Roper reminds the court, if an issue as to serious medical treatment arose within care proceedings then the relevant NHS Trust, seeking a medical declaration in respect of a child, would issue proceedings under the inherent jurisdiction in the normal way, which application would be heard at the same time as the care proceedings and determined solely by reference to the best interests of the child.

88. Although Mr Knafler chooses to compare the situation of the parents in inherent jurisdiction proceedings with those of care proceedings, it should not be overlooked that care proceedings are not the only statutory route whereby the court has jurisdiction to interfere with the exercise by a parent of their parental responsibility. Far more common than proceedings under section 31 of the Children Act 1989 are proceedings under section 8 of the Children Act 1989, Child arrangements orders and other orders with respect to children. Section 8.1 provides

"(1)In this Act —

"child arrangements order" means an order regulating arrangements relating to any of the following—

(a) with whom a child is to live, spend time or otherwise have contact, and

(b) when a child is to live, spend time or otherwise have contact with any person;

"a prohibited steps order" means an order that no step which could be taken by a parent in meeting his parental responsibility for a child, and which is of a kind specified in the order, shall be taken by any person without the consent of the court;

"a specific issue order" means an order giving directions for the purpose of determining a specific question which has arisen, or which may arise, in connection with any aspect of parental responsibility for a child".

89. Section 8, then, sets out the orders available to the court when resolving disputes between parties where a disagreement has arisen in relation to the exercise of parental responsibility. Such disputes are usually in relation to residence and contact following the breakdown of the relationship between the parents of a child, but also the section covers specific issue and prohibited steps order.

90. The resolution of every dispute under section 8 Children Act 1989 is determined by reference to the welfare principle enshrined in s.1 CA1989 whereby "the child's welfare shall be the court's paramount consideration." In other words, the decision is made by reference only to the best interests of a child.

91. It should not be thought that because section 8 applications fall outside s31 CA 1989 they cover only less serious matters than those dealt with by the courts under s31CA 1989 and the inherent jurisdiction. On the contrary, the courts hearing section 8 cases can and often do deal with allegations of the utmost seriousness relating, for example, to allegations of child sex abuse and domestic violence of every type from a verbal abuse up to and including marital rape and attempted murder.

92. Nor is section 8 limited to disputes between those parties who have parental responsibility. Third parties without parental responsibilities (for example a grandparent) can, with leave (granted under s10(2)(b) CA 1989) make applications under section 8.

93. Significant for the purpose of this present matter is that it is common ground that an NHS Trust can (with leave) seek a specific issue order under section 8 in a serious medical treatment case, as an alternative or more usually and preferably in parallel with an application under the inherent jurisdiction.

94. In *Re JM* [[2015](#)] [EWHC 2832](#), Mostyn J said:

"27. Therefore it seems to me that if the relief sought includes final binding declarations (which will normally be the case) then the application should be framed as a combination of an application for a specific issue order (seeking the necessary leave under section 10(2)(b)) and an application for declaratory relief under the inherent jurisdiction. This will allow the application to be issued directly in the High Court where it will be listed by the Clerk of the Rules before a full time High Court Judge."

95. Whether the dispute is with the third party without parental responsibility or the child's other parent with parental responsibility, the test is the same: "what is in the best interests of the child?" There is no threshold, whether of significant harm or otherwise.

96. During the course of section 8 proceedings it may become apparent to the court that additional factors are in play which are of more concern than the inevitable distress to a child upon family breakdown or in a medical treatment case, to the understandable chasm which has opened up between clinicians and parents unable to agree a way forward. The Children Act 1989 provides for just such an eventuality through section 37 Children Act 1989:

"37(1) Where, in any family proceedings in which a question arises with respect to the welfare of any child, it appears to the court that it may be appropriate for a care or supervision order to be made with respect to him, the court may direct the appropriate authority to undertake an investigation of the child's circumstances."

97. It follows, therefore, that where an application is made for a specific issue order under section 8 CA 1989, care proceedings - with the threshold of significant harm - provide the court with an additional avenue of intervention, only resorted to when there are concerns in respect of the child in question over and above the inherent difficulties which arise by virtue of the issue before the court.

98. Turning, then, to the inherent jurisdiction of the court, it is not necessary for the purposes of this judgment to embark on any thesis of the law relating to inherent jurisdiction.

99. As in section 8 cases, there is no threshold, and it is not necessary for a trust to prove significant harm before a court can make an order which would have the effect of interfering with the exercise of parental responsibility on the part of the parents. Decisions are made only on the basis of the best interests of the child.

100. Mr Knafler seeks to persuade the court that for parents with the status of these parents, care proceedings and proceedings under the inherent jurisdiction are appropriate comparators and that the situation for parents of children with serious medical issues can therefore be regarded as analogous. I do not agree. In my view, parents in care proceedings are not in an "analogous or relevantly similar situation" to those in medical "best interests" cases under inherent jurisdiction proceedings.

101. In my judgment care proceedings are part of the picture in medical treatment cases only in exceptional circumstances and as an adjunct of, or precursor to, an application under the inherent jurisdiction. The sort of devastating illness with which this court is concerned can and usually does come out of nowhere, regardless of whether the family is rich or poor, educated or uneducated, reasonable or unreasonable. The one thing these disparate families have in common is that it is "not their fault," and in my experience, even if their emotion is sometimes expressed inappropriately, they each and every one of them share a fierce devotion and protective instinct towards their vulnerable, often dying, child. These unhappy parents, finding themselves the victims of an appalling twist of fate, are not the type of parents who find themselves the subject of care proceedings.

102. By contrast, in care proceedings the harm in question comes about as the consequence of the actions or omissions of one or other or both of the parents, even if those parents are not truly culpable (as for example where they are significantly learning disabled and unable through no fault of their own to provide their child with "good enough" parenting).
103. Mr Knafler submits that care proceedings can be a jurisdictional route to the orders sought by the Trust (or any Trust) and it is this assertion that allows him to use care proceedings as an appropriate comparator. For this to be technically correct, the jurisdictional route would have to be through the use by the local authority of s33(3)(b) CA 1989 (see para [86] above). The withdrawal or treatment would have to come about as a consequence of the local authority consenting to the withdrawal of treatment as part of its care plan (approved by the judge) rather than by the making of a declaration on the application of the NHS Trust.
104. This use by the local authority of its powers under s33(3)(b) was not argued before the court. With respect to Mr Knafler, he argued the case on the basis that once care proceedings were launched, the court has the power to make such order as it thinks fit whereas the powers of the court are limited to the making only a care or a supervision order with all decisions in relation to parental responsibility thereafter resting with the local authority (together with the parents).
105. In my judgment in order for the court to be persuaded by Mr Knafler's jurisdictional argument, significant development of the argument would be necessary including reference to the issues raised in *Re C (Children)* [2016] EWCA Civ 374 (to which the court was not referred) a case dealing specifically with the limitations on a local authority to use s33(3)(b) in certain cases, including cases of serious medical treatment. This is however largely academic as, in my judgment, the absence of a developed argument in relation to the local authority's powers under s33(3)(b) does not affect my view that care proceedings are not, in any event, an appropriate comparator with the inherent jurisdiction in serious medical treatment cases.
106. In my judgment Mr Knafler is wrong to put care proceedings on the same jurisdictional plane as the inherent jurisdiction. Care proceedings are not a route to obtaining declaratory order as to future medical treatment. If a child who may also be the subject of an application for a declaration also becomes the subject of care proceedings, those proceedings will be one step removed in the same way as orders made under section 37 of Children Act 1989 are used in section 8 proceedings. That is to say where there is something more, some form of behaviour on the part of the parents, which necessitates the invoking of the child protection procedure found in section 31 of the Children Act 1989. Any application by a trust for a declaration will be dealt with by way of inherent jurisdiction and not within the care proceedings themselves.
107. Care proceedings in serious medical treatment cases will, and should, be issued only where there are significant additional issues of concern in respect of the care given by the parents to the child over and above a disagreement with the clinicians as to future care and treatment. Indeed, rightly in my judgment, it has been only in vanishingly rare cases that care proceedings have been issued in serious medical treatments, and I am myself unaware of any case where orders have been made within care proceedings in relation to serious medical treatment. If confirmation were needed, as long ago as 1993 Johnson J said in *Re O (a minor) (medical treatment)* [1993] 2 FLR 149 and 153:

"Counsel submitted that it was wholly inappropriate for the court to make even an interim care order where the child's parents were caring, committed and capable and only this one issue arose for decision, albeit of the gravest significance. Reflecting on the statutory provisions, and, in particular, s33, I accept that joint submission."

108. In *Re K (Children with Disabilities: Wardship)* [2012] 2 FLR 745, in what Hedley J referred to as a "highly unusual" case, the judge had before him care proceedings in respect of a family with several severely disabled children. The local authority had been involved with the family for many years and it was accepted that their involvement would continue indefinitely. Hedley J, having set out the terms of section 31 CA1989, said:

"24. Those provisions do not, of course, sit very easily with a case like the present. Significant harm is a real daily risk for A, AM & Z, but the incidence of such harm may

not, and usually will not, have any connection with the quality of care which is being given to them. It is incidental to their inherent conditions."

109. It follows that in my judgment Mr Knafler is wrong to approach the case on the basis that care proceedings are a first line jurisdictional choice or that these otherwise unimpeachable parents are in a 'relevantly similar situation' to parents whose child is the subject of care proceedings.
110. It was pointed out to Mr Knafler in argument that an essential feature of care proceedings is the so-called "attribution principle", in other words that the harm or risk of significant harm must be attributed to the care of the parent. Notwithstanding Hedley J's observation above, Mr Knafler submitted that the "attribution requirement" would not present a particular problem as, if the parents' proposal for the treatment for their child, rather than being simply sub optimum, was likely to cause significant harm, then the parents' failure to consent to the commission's alternative treatment plan would mean that the harm could be attributed to their care.
111. In my judgment, if there is any comparison to be drawn at all between the inherent jurisdiction and the statutory code found in the Children Act 1989 it is as between section 8 Child Arrangement Orders and the inherent jurisdiction, and not as between the inherent jurisdiction and care proceedings. There is in those circumstances a proper analogy, that is to say children and/or their parents in respect of whom medical treatment declarations are sought by NHS trusts. Each are judged by the same criteria, whether under the statutory scheme found in section 8 or under the inherent jurisdiction of the High Court, and there is therefore no discrimination under Article 14.

If care proceedings and the inherent jurisdiction are comparators and the situation of the parents is analogous, is there discrimination?

112. If I am wrong in my conclusion not only do Alfie and his parents have significant status for the purposes of Article 14, but the two sets of proceedings are in fact comparable and the parents in an analogous situation in both sets of proceedings, the next case would be for the court to consider whether or not there has in fact been discrimination. In my view, there has not.
113. In order to decide whether there is discrimination, it is necessary to bear in mind the circumstances in which such applications are made. As Lord Rodger said in *Carson*, courts should "look at the facts of the case as a whole and identify the particular issue or issues which have to be resolved in order to decide whether there has been discrimination or not." The chronology in this case reveals the strenuous attempts made by the Trust for a period of over 12 months in an attempt to reach a consensus with the parents as to how best to manage Alfie's inevitable death. To this end they commissioned independent reviews, they welcomed and cooperated with Dr Samuels and Bambino Gesù doctors nominated by the parents. In addition the Trust paid for outside expert mediators to work with the parents and themselves. It did this because the doctors and nurses caring for Alfie, in common with all clinicians in such a situation, aspire to work together with the parents and to support them rather than to be in conflict with them.
114. Applications for a declaration that the Trust will not be acting unlawfully by withdrawing treatment are made by hospitals in the knowledge that they can only be profoundly damaging to their relationship with the parents. Such applications are distressing, time-consuming, and expensive, and in order to pursue an application clinical staff and scarce resources are inevitably taken away from the children in their care.
115. Against this backdrop it is, in my judgment, inconceivable that a trust would contemplate withdrawal of treatment of a child leading inevitably to his or her death unless they were of the view that following the guidelines, his life was "futile".
116. Following this argument through, McCombe LJ in argument put it to Mr Knafler and to Mr Mylonas that it follows that in withdrawal of medical treatment cases just as much as in care proceedings, the court will not intervene to interfere with the exercise of the parents' parental responsibility absent the child's suffering or being likely to suffer significant harm. If attribution of that harm to the parents has been necessary it is to be found in their refusal to consent to the palliative care regime proposed by the Trust.

117. It will be recollected that in *Gard* Baroness Hale said,

"As the Court of Appeal found, it is in any event likely that Charlie will suffer significant harm if his present suffering is prolonged without any realistic prospect of improvement"

That finding had been made on the basis of very similar findings in relation to the issue of pain, as in the present case, namely that whilst it was unlikely that Charlie, or here Alfie, is suffering pain it cannot be ruled out.

118. Mr Mylonas disavowed such an analysis. Expedient though it would be, he says, to adopt McCombe LJ's exposition, he is unable to do so as the Trust is guided not by "significant harm" but by "futility" as found in the guidelines. In my judgment, much as Mr Mylonas is to be respected for his scrupulous refusal to seize upon what he believes to be a bad point in the name of expediency, such commendable fastidiousness on his part was unnecessary as the absence of a threshold is not, in my view, in any event discriminatory as the proceedings under the inherent jurisdiction have in my view an objective and reasonable justification and pursue a legitimate aim, namely the care and treatment of desperately ill children.
119. Again it was not argued before the court but, notwithstanding Mr Mylonas' circumspection, it seems to me that there may be a respectable argument that when it comes down to significant harm in the context put by McCombe LJ to Mr Mylonas when put side by side with "futile" may in this context be different labels but without distinction.
120. I am satisfied, therefore, that even if the position of the parents in the current care proceedings under the inherent jurisdiction have been analogous there has been no discrimination. What would the position have been had there been, could it be justification?

Justification

121. Mr Knafler argues that whether the State acts under parts IV and V of the Children Act 1989, Care proceedings, or under the inherent jurisdiction, it is ultimately and essentially doing the same thing, namely intervening in the life of the family in order to safeguard and/or promote the welfare of a child in a manner inconsistent with that which the parents would wish. There is, he submits, no proportionate justification for the different approaches for overriding parental choices.
122. Setting aside for a moment my view that the two procedures are not two sides of the same coin, and therefore comparable, and that even had they been so there is no true discrimination for the reasons set out above, I do not accept the submission that it is not proportionate and that there is no justification for such discrimination in cases of serious medical treatment for children. In *In the Matter of M (Children)*, [2017] EWCA Civ 2164, Sir James Munby, the President of the Family Division, said:
- "109. In assessing whether an apparently discriminatory measure or decision is objectively justified it will be important to scrutinise the evidence that is proffered by way of justification, in particular to see whether it amounts to any more than the merely subjective attitudes of other people."
123. Mr Knafler reminds the court that it is not necessary for the parents to establish a breach of their Article 8 rights in order to make out their case under Article 14, and argues that absent any identifiable policy to justify the alleged discrimination, the difference in treatment is not objectively justifiable but rather represents the subjective attitudes of the doctors in the case in relation to the care of terminally ill children. Such attitudes are, he accepts, held by many, but equally he submits, rejected by many of the general population and by many in respected positions both here and abroad.
124. Mr Knafler was frank in accepting that a consequence of his approach would be that where a parent did not agree with the hospital's treatment plan, even where the plan had been endorsed by their own independent experts, the parents could insist on what Mr Knafler has termed "suboptimal" care. In other words, the best interests of the seriously ill child must, he says, take a secondary position to the wishes and feelings of their parents absent attributable significant harm. With respect to Mr Knafler, not only does such an approach feel instinctively wrong, but it must be recollected that not only do the

parents have rights, but so does the child, Alfie, and European law has been consistent in saying that the best interests of a child, whether seriously ill or not, must take primacy.

125. In *Gard* the ECHR said in relation to the margin of appreciation:

"83. The Court notes that no consensus exists among the Council of Europe Member States in favour of permitting the withdrawal of artificial life-sustaining treatment, although the majority of states appear to allow it. While the detailed arrangements governing the withdrawal of treatment vary from one country to another, there is nevertheless consensus as to the paramount importance of the patient's wishes in the decision making process, however those wishes are expressed see *Lambert* (2016) 62 [EHRR 2](#) at [147]

84. Accordingly, the Court considers that in this sphere concerning the end of life, as in that concerning the beginning of life, states must be afforded a margin of appreciation, not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of the patient's right to life and the protection of their right to respect for their private life and their personal autonomy... However, this margin of appreciation is not unlimited (at [238])... and the Court reserves the power to review whether or not the state has complied with its obligations under art.2 (*Lambert* (2016) 62 [EHRR 2](#) at [148] "

126. It follows that the State has a wide margin of appreciation as to how the withdrawal of life-sustaining treatment is managed, unaffected by the fact that other states, in this case Professor Hass asserting such an approach is taken in Germany, may have very different approaches or views as to how and if treatment should be withdrawn, and if so in what circumstances. In the United Kingdom such cases are managed within the hospitals in accordance with guidelines, which guidelines operate under the law which states that the best interests of the child are the determining factor. In the event that there is disagreement the matter is referred to the court, where both the parents and the child are parties to the proceedings.

127. In my judgment the need to place the best interests of a seriously ill child (objectively, and independently assessed) ahead of the wishes of even the most devoted and caring of parents provides objective justification for any difference between care proceedings and the inherent jurisdiction.

128. In conclusion, then, whilst I would grant permission to appeal in relation to this part of Ground 1 only, I am satisfied that the law as applied to applications under the inherent jurisdiction for declarations that it is lawful to withdraw treatment is not in breach of Article 14.

129. Accordingly, permission to appeal is refused save in respect of Ground 1, paragraph 2. Permission to appeal on that one sub-ground is granted, but the appeal is dismissed.

LORD JUSTICE M^cCOMBE

130. I agree with my Lady's judgment and with the order which she proposes.

LORD JUSTICE MCFARLANE

131. I agree that permission to appeal should be granted on Ground 1, paragraph 2 only, and that the appeal on that ground should be dismissed for the reasons given by my Lady, Lady Justice King.

132. The "Postscript" which now follows relates to matters which call for comment from this court, but which have played no part in our determination of this appeal. The remainder of this judgment is the judgment of the court, to which all three members have contributed.

Postscript

133. As Lady Justice King has recorded, on two separate occasions Alfie's father brought doctors whose practice is in a foreign jurisdiction into the Paediatric Intensive Care Unit at Alder Hey hospital for the purpose of conducting a clandestine medical examination of this profoundly ill child. The first such examination was conducted by Dr Matthias Hubner on 11 December, and the second was by Dr Jankowska (and possibly a second doctor) on 20 January 2018.
134. Last week this court [Lord Justices Patten and McFarlane and Lady Justice King] gave judgment in another case involving a child whose life was entirely dependent upon artificial ventilation, *Re Isaiah Haastrup* [2018] EWCA Civ 287. Although Isaiah was a patient in King's College Hospital in London, some 200 miles from Alfie in Liverpool, and although so far as the court is aware, there is no connection between the two children or their families, Isaiah Haastrup was also visited and examined by Dr Jankowska and two other individuals on 20 January 2018, in circumstances which the hospital regarded as wholly clandestine. The court was told that the King's College Hospital Trust had reported the incident to the police on the basis that a criminal offence under the Medical Act 1983, section 49, may have been committed, and also reported it to the General Medical Council.
135. A report from Dr Hubner advising that the child was fit to fly had been submitted to the court in Isaiah Haastrup's case, although it was not clear whether or not Dr Hubner had examined Isaiah at KCH.
136. Although these two cases have come on for hearing before this court within the same two-week period, we do not regard the similarities in what is reported regarding clandestine medical examinations being conducted on these seriously ill children as being a coincidence. The links between the activities of the foreign doctors and the unnamed "supporters" who have introduced them to the parents in each case are, in our view, plain.
137. In both cases the purported examination of the two children was conducted without permission of the court and without any consultation with or approval from the medical team caring for the child.
138. In addition, in each case a number of unidentified yet plainly incomplete notes or records were disclosed to the doctors in question, again without permission.
139. The unknown supporter who, it is said, introduced Dr Hubner and Dr Jankowska to the families also recommended Dr Haas in each case. In the present case Dr Haas provided an opinion with permission from the court, although in *Haastrup* the mother's legal team sought permission to rely upon the report following unauthorised disclosure of the papers to him.
140. In both cases Dr Haas advanced similar views based on specific issues in German history upon which he rested his different "cultural approach".
141. In the *Haastrup* case the judge found that the mother's solicitor had been directly involved in providing information to arrange other doctors without the leave of the court.
142. It is thus the case that this court is now aware of two cases where in recent weeks and in similar circumstances a profoundly ill child at the centre of contested court proceedings has been visited by a doctor or doctors without the knowledge of the other parties, without the authorisation of the court and, most importantly, without the knowledge of the treating clinicians, in a clandestine manner with a view to that doctor conducting a medical examination of the child and thereafter providing evidence for the court proceedings.
143. For over 25 years the family courts have maintained a tight control on the instruction of experts. The current legislation is contained in an Act of Parliament, the Children and Families Act 2014, section 13, which reads as follows:

"1. A person may not without permission of the court instruct a person to provide expert evidence for use in children proceedings.

2. Where a contravention of subsection 1 a person is instructed to provide expert evidence, evidence resulting from the instructions is inadmissible in children proceedings unless the court rules it is admissible.

3. A person may not without the permission of the court cause a child to be medically or psychiatrically examined or otherwise assessed for the purposes of the provision of expert evidence in children proceedings.

4. Where in contravention of subsection 3 a child is medically or psychiatrically examined or otherwise assessed evidence resulting from the examination or other assessments is inadmissible in children proceedings unless the court rules that it is admissible."

144. In cases such as the present, the judges of the Family Division habitually and rightly extend a very broad tolerance to, and respect for, the position of the parents of a terminally ill child. It is rare for such a parent to be criticised by a judge, no matter what they may say or do in furtherance of their case. Neither MacDonald J nor Hayden J criticised the parents in either the *Haastrup* case or the present case in relation to the clandestine medical examinations. We do, however, feel driven to observe that, where a doctor is clandestinely introduced to a paediatric intensive care unit for the purposes of conducting a medical examination of a child who is the subject of court proceedings, a line has plainly been crossed, with such behaviour being wholly unacceptable.

145. We should be clear that we make these comments not from any desire simply to enforce the court rules governing the instruction of medical experts. The issue is, in our view, of an altogether higher level of concern. We draw attention to the following four factors:

i) How is a parent to know whether a person to whom they are introduced for this purpose is indeed a doctor, as opposed to another individual who may have an altogether more malevolent interest in gaining access to a seriously ill child and purporting to conduct a medical examination upon them in the highly vulnerable circumstances of a PICU? The potential for the child's safety to be significantly compromised by the parent's actions is, to our mind, all too plain.

ii) The doctors concerned, together with the parents and their legal advisers, may be exposing themselves to prosecution for criminal offences, disciplinary proceedings or contempt of court by arranging or taking part in a clandestine medical examination of a profoundly sick child, in a specialist hospital unit during the currency of contested court proceedings relating to the child's treatment.

iii) Evidence gathered in this wholly unacceptable manner is most unlikely to be afforded any weight by the court deciding upon the child's future medical treatment. As Mr Knafler readily conceded, Dr Hubner's evidence was, rightly, totally discredited once it had been examined by the court. In the circumstances, it is difficult to understand what of benefit to the parent or to the child is to be gained by involving an outside medical expert in this way.

iv) There should be, and in our experience there is, no need for parents to resort to any form of clandestine activity if they wish to have their child examined by an additional medical expert. The treating hospital will normally welcome the involvement of relevant outside expertise and they will cooperate fully by the provision of full medical notes and facilities for examination, just as Alder Hey did with respect to Dr Samuels and the team from Bambino Gesù. The courts also frequently permit the instruction of additional experts on behalf of the parents (as did Hayden J in relation to Dr Haas in this case).

146. Now that the unwelcome and, we would say, dangerous development of supporters encouraging parents to arrange for those without authority to conduct secret medical examinations of these very vulnerable children has come to light, we consider that it is appropriate to record our condemnation of this practice. Irrespective of the extreme nature of the issue before the court, in future cases the parents and those representing them should expect the judge to refuse permission for evidence obtained in this clandestine manner to be admitted in the proceedings. In any event, as was the case both in the present proceedings and in *Haastrup*, the court is unlikely to afford much, if any, weight to a medical examination that is conducted in such circumstances or to the opinion of a doctor who has acted in this wholly unprofessional way.

Order: Application refused on all grounds except ground 1(2) which is granted; appeal dismissed
