Neutral Citation Number: [2018] EWHC 308 (Fam)

Case No: FD17P00694

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 20th February 2018

Before :

MR JUSTICE HAYDEN

- -

Between :

Alder Hey Children's NHS Foundation Trust **Applicant**

- and -

1) Mr Thomas Evans
(2) Ms Kate James
(3) Alfie Evans
(A Child by his Guardian CAFCASS Legal) **Respondents**

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Michael Mylonas QC (instructed by **Hill Dickinson)** for the Applicant
The First and Second Respondents representing themselves
The Third Respondent represented by Ms Melanie Carew of CAFCASS
Hearing dates: 1st and 2nd February 2018 & 5th – 9th February 2018

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Judgment Approved

MR JUSTICE HAYDEN

This judgment was delivered in public. The judge has given leave for this version of the judgment to be published.

Mr Justice Hayden :

1. I am concerned here with an application made on behalf of the Alder Hey Children's NHS Foundation Trust concerning Alfie Evans who was born on 9 May 2016. The Trust seek a declaration that continued ventilatory support is not in Alfie's best interests and in the circumstances it is not lawful that such treatment continue.

2. Alfie's parents, Tom Evans (F) and Kate James (M), both resist the application. In the hope of resolving the dispute and endeavouring to forge an agreed resolution, a mediation meeting took place on the 8 January this year. No agreement as to the way forward was forthcoming.

Background

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.

4. The first indication that all might not be well occurred in July 2016 when Alfie was noted to have a 'divergent squint' for which a hospital referral was considered appropriate. He was seen again by his General Practitioner, at four months, for his first child development check. It is clear that M already had some concerns about her son's general development. Alfie's smile had become less frequent, he was sleeping to an extent that had begun to alarm her and quite commonly she had to wake him up. She was concerned too with Alfie's lack of general interaction and disinclination to reach out for or play with his toys. I sense also that M considered that the squint was something rather more serious. She queried Alfie's ability to see. It is apparent that concern was shared by others, the health visitor was troubled by Alfie's lack of age-appropriate head control.

5. By six months of age there was no doubt that Alfie was showing marked signs of significant developmental delay. He was reviewed in the general paediatric outpatient clinic in Alder Hey Hospital in November 2016. On examination he was there found to be functioning in a range appropriate to a six week – 2 month old infant. An MRI brain/spine scan was arranged for 30 November 2016. The report of Dr M, a Consultant Paediatrician, specialising in intensive care medicine, records the following:

> *"The MRI brain scan done on 30.11.2016 showed evidence of borderline delayed myelination for his chronological age and unexplained diffusion restriction along sensory motor cortex, the cortical-spinal tracts and fibres leading into the medial temporal lobes. The appearances were not typical for any specific disorder. Suggested possible diagnoses to be excluded included mitochondrial disorders and non- ketotic hyperglycinaemia."*

6. On 14 December 2016 Alfie was admitted to Alder Hey Accident and Emergency Department with a history of coughing, high temperature and a reported episode of rhythmic jerking of all four limbs and his jaw. His parents reported that this episode had lasted approximately 20 minutes, after which Alfie had a sleep. He was taken to Accident and Emergency about 20 minutes after the episode. The following is recorded in the paediatrician's report:

> *On review in the Accident and Emergency Department, Alfie was noted to have a temperature of 38.4^{0}C (normal body temperature 37^{0}C) and he was tachypnoeic (fast breathing rate) with a breathing rate of 60 breaths per minute. (The normal breathing rate for this age is 20 -30 breaths per minute). He had moderate increased work of breathing with signs on auscultation (listening) to the chest of wheeze and scattered crepitations (crepitations are heard with secretions in the lungs). A microbiology test on a nasopharyngeal aspirate (NPA) showed rhinovirus/ enterovirus. (The test*

cannot differentiate these two organisms - infection could be with either or both pathogens). We commonly isolate these viruses in infants with acute viral lower respiratory tract infections. Alfie was diagnosed with acute viral bronchiolitis and a possible prolonged febrile convulsion.

7. Later in the afternoon Alfie was observed to have episodes of jerking of his whole body and referred to the Neurology team. An EEG was requested and the plan was to commence anti-convulsant therapy if the seizures worsened. On 15 December 2016 the seizures continued to the degree that it was thought necessary to prescribe Midazolam which is a benzodiazepine which is, I am told, a first line drug. This was administered for Alfie via the buccal route (placed against the inside lining of the cheek) which enables rapid absorption for patients who do not have an intravenous cannula. The medical records reveal that the seizures stopped after two or three minutes and Alfie slept.

8. There were more problems overnight on the 16 December 2016 and after discussion Alfie was commenced on a different anti-convulsant, Vigabatrin. On the 19 December Alfie was reviewed by Dr R, a consultant in paediatric neurology and on examination was found to have a slow breathing rate, apnoeas (pauses in breathing) and his most significant identifiable neurological response was to pain. The plan was to transfer Alfie to the High Dependency Unit for non-invasive respiratory support. Whilst preparing for this Alfie's condition deteriorated significantly, his heart rate dropped and the periods of apnoea became more prolonged. A cardiac arrest call was made and bag-mask-valve ventilation was commenced to support his breathing.

9. When the cardiac team arrived, the anaesthetist took over management. Nasopharyngeal and Guedel airways (an oral airway adjunct to maintain or open a patient's airways) were inserted and Alfie was given oxygen via a mask. In addition the plan to admit Alfie to HDU was abandoned and he was transferred to the Paediatric Intensive Care Unit (PICU). Dr R has given a summary of this period in a statement filed in this Application. It requires to be stated in full:

"I saw Alfie with his parents on the 15th December 2016. He showed sudden unprovoked movements compatible with infantile/epileptic spasms. An EEG performed on the 16th December 2016 confirmed hypsarrhythmia (electrical correlate to clinical epileptic or infantile spasms, disorganised EEG). The EEG captured a number of electro-clinical epileptic spasms. I commenced Alfie on Vigabatrin (anti-epileptic medication, first line treatment for infantile/epileptic spasms) with an increasing dose regime as per standard practice. Alfie did not show any neurological recovery following the severe respiratory deterioration and critical life threatening illness on the intensive care unit. Alfie showed signs of a severe infantile progressive encephalopathy with drug and ketogenic diet resistant seizures. He remained profoundly encephalopathic/ comatose and remained unresponsive to central noxious stimuli (i.e. painful/ uncomfortable stimulation delivered via rubbing of cranial nerve exit points in the area of his eyebrows) . Encephalopathy is a general term that refers to brain malfunction due to brain disease or brain injury. The major symptom of an encephalopathy is reduced responsiveness or an altered mental state. Epileptic seizures and a movement disorder can also be a symptom of an encephalopathy. There are numerous causes for an encephalopathy in

childhood. They include infections, brain malfunction due to lack of oxygen or reduced blood flow, metabolic and biochemical conditions, toxins, drugs, trauma, and neurodegenerative diseases. At times Alfie showed withdrawal of his legs to peripheral noxious stimuli (ie applying pressure to his nailbeds) and presumed spinal reflexes. This means that information of painful stimuli travel up the nerve, enter the spinal cord in the back and stimulate a motor response, i.e. withdrawal, extension or flexion, via exiting immediately through the frontal nerve roots in the spinal cord without being modified from central "higher" nerve cells in the brain. Similar to our immediate withdrawal to for example, touching a hot cooker plate, when we withdraw our fingers long before we realise there is pain. The majority of responses to tactile stimuli or to eye opening/light exposure were and are seizures as confirmed on repeated EEG examinations."

10. A further EEG was performed in January 2017. This, however, was markedly different, showing attenuation with little in the way of reactive response for protracted periods of time. Changes only really occurred when Alfie had an epileptic seizure. Though there was no period of collapse between December and January all are agreed that Alfie was very unwell with a severe bi-lateral pneumonia. It was at this time that the treating clinicians thought it both necessary and appropriate to broach with the parents the real possibility that Alfie might not recover. In fact Alfie did not succumb to the pneumonia and effectively fought off the infection. This has become an absolutely crucial feature of Alfie's treatment in the father's mind. 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 F has been critical of the doctors for having that conversation with him which he believes to have been premature. He perceives this as "the hospital giving up on Alfie".

11. Though Alfie had successfully resisted the viral infection it is the case that the EEG pattern did not change and indeed has remained largely static since. Dr R characterises Alfie's present condition as showing no response to tactile, visual, auditory or sensory stimulation. He has concluded that Alfie is in a coma and thus unaware of his surroundings. By January 2018, the pupillary response was, he considers, "*entirely abnormal with only the most subtle, brief dilatation to light without any normal constriction.*" Some of this is disputed by Mr Evans.

12. In his evidence Dr R told me that Alfie does not respond to loud noises, central painful stimuli or peripheral stimuli, he is profoundly hypotonic (abnormal loss of muscle control). Such response as there is Dr R considers to be entirely seizure related. All this is reflected in the EEG graphs.

13. In the light of the parents real and entirely understandable concern about the underlying neurological diagnosis, Professor Judith Cross was instructed independently to review the clinical history, the EEG's and the serial MRI's. I shall turn in more detail to the MRI scans shortly but it is beyond doubt that they confirm a 'rapidly progressive destructive brain disease'. Professor Cross is presently the Prince of Wales' Chair of Childhood Epilepsy at UCL - Great Ormond Street Institute of Child Health. She is also Honorary Consultant in Paediatric Neurology. She reviewed Alfie at the PICU on 15 June 2017.

14. In addition to the above Professor Cross reviewed the birth records and the family history.

She noted that the MRI scan performed on 30 November 2016 raised the possibility either of underlying degenerative disorder or alternatively a metabolic disorder. Mr Evans, during his cross-examination of the Trust's witnesses, has focused on the possibility of the latter, identifying metabolic disorder as the diagnosis which permits of a more optimistic prognosis. In her evidence Professor Cross told me that she reviewed the serial EEG investigations. She emphasised that there is a 'striking' and 'marked' distinction between those of December and those post-January. Those in December reveal evidence of hypsarrhythmia i.e. activity, particularly during sleep. However, in January (2017) Professor Cross was clear that there was little in the way of reactive response. The EEG she told me was *"markedly attenuated"* which she clarified as "*essentially flat"*. The only identifiable activity followed immediately upon epileptic seizure and quickly disappeared.

15. Both Professor Cross and Dr R have emphasised the evidential significance of the MRI scans. Both doctors but Dr R in particular volunteer that the scans, whilst important diagnostically, also have to be considered in the broader context of Alfie's clinical presentation and history. A number of scans were undertaken. The first, as I have stated above, was dated 30 November 2016. The second was in February 2017. The third scan was performed on 22 August 2017 and was significant. When Professor Cross gave her evidence the August scan was the most recent. Because that scan was now nearly six months old I asked if a further MRI scan could be taken in order that I had the most up-to-date evidence. I was reassured by Dr R that this would not be an intrusive or unsettling investigation for Alfie. The most recent scan is dated 2 February 2018. The earlier scans seen by Professor Cross enabled her to interpret the following:

> *"bi-lateral symmetrical mid-brain lesions, central tegmental tracks within the brain stem, global pallidus, thalami and striking symmetrical restricted diffusion in the mesial temporal lobes, perirolandic cortices"*

The later imaging however showed:

> *"diffuse white matter signal abnormality and swelling with swelling of the globus pallidi, haemorrhagic infarction in the globus pallidus and splenium with thalamic atrophy"*

The most recent scan seen by Professor Cross i.e. that of the 22 August 2017 she considered was highly indicative of a neurometabolic disorder, particularly a mitochondrial disorder showing rapid progression. These complex interpretations of the brain function were distilled into clear and inevitably distressing language. The analysis led to a bleak conclusion.

16. Professor Cross concluded that Alfie has a progressive, ultimately fatal neurodegenerative condition, most likely a mitochondrial disorder. During her cross-examination by F she told him in gentle terms that even if it were possible to stop Alfie's seizures, which did not look likely given his poor response to anti-convulsant 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 it is simply acknowledged by neurologists that it cannot. F, who has been representing himself and his partner during this case for reasons

which I will address in detail, followed this observation up by enquiring whether given that Alfie's brain has not yet (at his age) fully formed it might generate as oppose to regenerate brain matter. That was just one of F's many thoughtful and impressive questions of the medical experts. Sadly, it drew a negative response. The brain would only be able to generate further from existing matter.

17. Professor Cross surveyed the broader canvas of evidence. She noted the deterioration in Alfie's respiratory effort. It is unlikely that he can breathe now without assistance. She factored in the dramatic deterioration in the EEG scans. All this she concluded pointed to a mitochondrial disorder. This she recognised had now been further supported by tests indicating mitochondrial genetic mutation. Nothing in the brain was functioning normally. Professor Cross considered that the brain was now only able to generate seizures. Accordingly, this was not an epileptic encephalopathy by which Professor Cross explained that the epileptic seizures are not contributing to the neurological degeneration but a consequence of the neurodegenerative disorder.

It is important to highlight Professor Cross's ultimate conclusion clearly. She told me that *"even if Alfie is able to sustain respiration in the short term, on discontinuing ventilation, his respiratory effort will not sustain life."* She amplified this by stating that were Alfie to manage for the short term his brain will not recover in any event and he will continue to deteriorate with extremely short life expectancy. The following requires particular emphasis:

> ***"All investigations have been performed that would have demonstrated a remediable or treatable cause and even if at this stage there was something to treat his brain the neurological function will not show any degree of recovery. I appreciate this news will be extremely difficult for the family. I do not feel further therapy is going to have an impact on seizures and even if seizures were reduced this is not going to change [Alfie's] outcome."***

18. The parents have, both in the course of these proceedings and in preparation for them, explored opportunities for alternative opinions. In particular they have instructed, through their solicitors who were acting at the time: Dr Martin Samuels (Consultant Respiratory Paediatrician); the Senior Clinical Team at the Ospedale Pediatrico, Bambino Gesu (BG) (Rome); Dr Matthias Hubner, Medical Director, Pediatric Air Ambulance, Amtsgericht Munchen; Professor Nikolaus Haas, Medical Director, Department of Paediatric Cardiology and Intensive Care, University Hospital Ludwig-Maximilians university (LMU) Munich.

19. It is recognised that all the doctors have come to the conclusion that Alfie is suffering from a neurodegenerative disorder. Nobody knows what triggered or caused this devastating erosion of Alfie's brain, there is no diagnosis and there may never be. The fact remains however that all agreed the degeneration is both catastrophic and untreatable. Professor Haas's report, dated 7 January, was filed in consequence of my own case management decision on the 19 December in response to the parents' application. At that time both were represented by highly experienced solicitors and Counsel. At the hearing the specialism of the required expert was agreed but I permitted the parents' team to identify

the individual. In the light of the broad consensus I do not consider it necessary to review the evidence of each of the witnesses. It is however important that I identify the conclusions of Professor Haas. At the hearing the Court staff spent several days trying to contact Professor Haas who was returning from an international conference. He had not been warned to attend to give evidence by F. Contact was made and Professor Haas was ready to commence his evidence by telephone link. At the very last minute F decided that he did not wish to challenge Professor Hass's evidence. In setting out these arrangements I do not intend to be critical of F in any way, but it is important that it is recorded that every effort has been made in order for him to develop his case as fully as possible.

20. Professor Haas expresses his opinion in succinct and clear language:

> *"There are numerous excellent statements of the assessment of Alfies condition in the file from many distinguished specialists in the field of paediatrics, paediatric epilepsy, intensive care etc. which I will not copy and discuss again. These specialist are mainly from the distinguished Alder Hey Children's hospital in Liverpool as well from other well known specialist hospitals in the UK and the Vatican (Ospedale Pediatric Bambino Gesu). In summary i t is clear - based on my assessment and on these reports - that Alfie suffers from a progressive, very likely ultimately fatal neurodegenerative disorder of so far unknown origin. There have been numerous test performed, unfortunately without any possibility to give the disease a known name (maybe this disease will be ultimately named after him - Alfies disease)."*

21. In a passage which seems to me to engage directly with the parents' case in a manner intended to help their understanding as well as to confront their misgivings, Professor Haas sets out the central conflict thus:

> *"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 Alfies 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.*
>
> *e. Alfie's inability to breathe is a consequence of the disease and not likely from the medication administered.*
>
> *f. there are by all means no thinkable treatment options available that would stop or reverse his underlying disease."*

22. Finally, two further passages require recording:

> *" I do fully support the assessment of the neuropediatric team that the seizure activity is caused by the progressive neurodegenerative disorder and not vice-versa. It is well known and perfectly explained by others….that seizures in these circumstances are very difficult or even impossible to control.*
>
> *The colleagues have tried several combinations of antiepileptic mixtures with limited success. As the seizures are however not under control yet, other treatments or different "cocktails" of antiepileptic drugs may well be considered and tried. It may also be difficult for the parents to understand, but in my opinion there is little if any to offer".*

23. As to the possibility of any further testing Professor Haas could not be clearer:

> *Based on the extensive testing already performed, I do agree with the medical teams involved that there are no useful test that may be performed to improve Alfie's condition. The genetic testing (i.e. whole genome sequencing) is performed by blood sampling and without any risks for Alfie. These tests may in certain cases be beneficial to delineate a new rare disease as pointed out by the doctors of the Bambino Gesu Hospital. To the best of my knowledge these test have - even if a new disease is found - never been able to cure a patient with a similar disease pattern as Alfie shows.*

Notwithstanding that Professor Haas has assessed Alfie's medical circumstances in terms which are identical to those at Alder Hey he has different views as to what he terms *"withdrawal of therapy"* and which I shall call end of life plans.

The Medical Consensus

24. Dr Samuels filed a report which was, as I have said, solicited by the parents. F required him to attend to give oral evidence. If I may say so I thought that was a proper course for F to take. However, Dr Samuels is very clear that Alfie's prognosis is futile. He notes that BG describes him as being in a ***"semi-vegetative state"*** *(my emphasis).* For Dr Samuels the greatest concern was the possibility of any potential suffering that Alfie may be experiencing. He considered that the high quality intensive care that Alfie is receiving at Alder Hey could *"sustain him for a long time".* He noted that there is the *"potential for acute infection e.g. sepsis, or hypoxia relating to seizure to cause sudden deterioration and death".* Dr Samuels stressed, both in his report of 10 December 2017 and in his oral evidence, that movement, light and sound can produce physiological change in Alfie for which he posited three potential explanations: basic reflex; seizure related activity; association with discomfort. Whichever was most likely Dr Samuels considered that the appropriate course was to offer palliative care to Alfie. This he considered would best be served by symptom management i.e. keeping Alfie comfortable and withdrawal of ventilation and intensive care. In his thinking the combination of the futility of Alfie's life (i.e. the absence of any prospect of recovery) and the uncertainty of knowing whether Alfie is suffering were key factors.

25. Dr M in her report, dated 20 December 2017 (see para 5 above), sets out her conclusions and opinion. Though she amplified these in her oral evidence they remained essentially the same:

> *"My opinion, based on Alfie's presentation, clinical deterioration and progression of his MRI scan appearances and the expert opinion of a number of paediatric neurologists is that Alfie has a progressive neuro-degenerative disorder from which there is no hope of recovery. This opinion is supported by clinical experts both within Alder Hey Children's Hospital and from independent national and international experts who have reviewed Alfie. It also the consensus opinion held by the entire medical consultant body on the Paediatric Intensive Care Unit at Alder Hey.*
>
> *It is my opinion (and that of my intensive care consultant colleagues), that Alfie has a poor quality of life. He is completely dependent on mechanical ventilation to preserve his life. He has no spontaneous movements, cannot communicate and continues to have frequent seizures. I believe that is it unlikely that Alfie feels pain or has sensation of discomfort but I cannot be completely certain of this since Alfie has no way of communicating if he is in pain or discomfort. I believe that given Alfie's very poor prognosis with no possible curative treatment and no prospect of recovery the continuation of active intensive care treatment is futile and may well be causing him distress and suffering. It is therefore my opinion that it is not in Alfie's best interests to further prolong the current invasive treatment. It would, in my opinion, be appropriate to withdraw intensive care support and provide palliative care for Alfie for the remainder of his life."*

26. It is important that I address the evidence of Dr R. He was the primary witness for Alder Hey Hospital. He has been present in the Court throughout the entire hearing. He chose to remain, along with Dr M, even after I had released him from attendance. That proved to be fortunate as he later had to be recalled in response to F asking me to admit new evidence. Dr R impressed me as a thoughtful, kind and extremely conscientious Consultant. He responded to the obvious challenge of being questioned directly by a grieving parent in a public Court room with patience, compassion and great professional skill. Without exception he displayed a willingness to reflect carefully on the questions and propositions put to him and a readiness to yield to any point that might be made against him. F was unsparing in some of his challenges to Dr R, suggesting collusion with other doctors and sometimes seeking to cast doubt on his integrity. Expressed in this way it appears to reveal F in an unfavourable light but these assays have to be tempered against F's essential courtesy and good manners throughout. I observe that, whilst it may not seem entirely consistent with the case he advanced, F consistently paid tribute to the medical and nursing staff. This apparent contradiction, which I have already highlighted, is explained by the extremity of F's grief which is raw and intense.

27. Alfie has been extensively investigated. Dr R comments:

> *"Investigations have been reviewed both by internal and external experts in the field of paediatric neurology and infantile epilepsies. No further investigations were recommended for him other than the further molecular genetic testing to further investigate the potential diagnosis of early infantile Batten disease. Further results from Great Ormond Street Hospital in London have since returned negative results."*

28. In his report dated 20 December 2017 and in his evidence in chief Dr R considered that the MRI scans which I have addressed above confirmed the progressive degeneration of Alfie's cerebrum and cerebellum. He told me that he had decided not to undertake a further MRI scan because it would not be of any benefit to Alfie nor would it assist in confirming the diagnosis. He considered the existing MRI scans required no further amplification. Moreover, F had indicated to the hospital that he did not want any further scans. Dr R considered that a further MRI scan would solely serve the purpose of plotting Alfie's neurodegenerative decline. As emerges I took a different view. Crucial to the decision I am being asked to make is the need to ascertain, as accurately as it can be, the present level of Alfie's awareness. Accordingly, I considered that an up-to-date MRI scan was a significant component in the broad sweep of evidence that was likely to inform this assessment. The scan of 2 February 2018 confirmed the progressive destruction of the white matter of the brain which Dr R interpreted as now appearing almost identical to water and cerebrospinal fluid (CSF). In addition, new areas of signal abnormality were demonstrated in the deep grey matter of the basal ganglia. The thalami, which I have been told fire the pathways within the white matter which generate sensory perception is, Dr R points out, effectively invisible in the scan. In simple terms the thalami, basal ganglia, the vast majority of the white matter of the brain and a significant degree of the cortex have been wiped out by this remorseless degenerative condition.

29. Painful though it is for F to read Dr R's observations of Alfie's current condition, it is necessary for me to set them out:

> *"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 are spinal reflexes. He is deeply comatose and for all intents and purposes therefore unaware of his surroundings. Although fluctuating, his pupillary responses are abnormal with now only the most subtle, very brief dilatation to exposure to light but no normal constriction. Exposure to loud noises does not elicit any response. There is no response to central painful stimuli other than the occasional seizure. There is no response to painful peripheral stimuli other than seizures or at times spinal reflexes with extension and internal rotation of his arms and less frequently now, of flexion of his legs. Alfie is profoundly hypotonic (low muscle tension at rest). Deep tendon reflexes are absent. There is no ankle myoclonus and no evidence for spasticity (movement induced increase in tone).*
>
> *Alfie's brainstem function appears to be intermittently impaired with episodic periods of bradycardia, which are currently self-resolving. The brain stem controls vital functions such as heart rate, blood pressure, temperature among others. Alfie has not lost brainstem control as he does not show signs of temperature instability, diabetes insipidus (i.e. loss of central control to concentrate urine) or abnormalities of sugar control. Episodes of otherwise not explained low heart rate point to an impairment of brainstem function suggesting that very rudimentary functions are at least intermittently impaired. This is not unusual. This does not imply that Alfie is able to "enjoy sensations", it just means that very basic functions are impaired. When there is severe impairment of the brain during for example severe hypoxic/ ischaemic events, the brain "shuts down" any non essential perfusion ensuring that the brainstem continuous to be supplied with blood flow and oxygen to preserve vital functions to "preserve life" Alfie does not currently show other brainstem dysfunction such as temperature de-regulation, excessive sweating, abnormal skin perfusion*

(flashing or extreme pallor), de-regulation of his glucose (sugar) levels or dysregulation of his fluid haemostasis (no evidence for diabetes insipidus with excessive urine output and electrolyte disturbances).

30. I also consider it necessary to set out the full gamut of the challenges that Alfie faces which are properly chronicled in Dr R's report, the vast majority of which are not challenged by the parents:

Alfie has no gag reflex and is unable to swallow or manage his oral secretion effectively. Alfie is one hundred per cent dependent on ventilator support. Attempts at weaning ventilation with a view to extubation (taking the endotracheal tube out) have failed on a number of occasions. From a cardiovascular perspective, apart from intermittent episodes of bradycardia (low heart rate) which are self-resolving, Alfie's cardiovascular observations remain stable with normal central and peripheral perfusion and blood pressure.

From a gastrointestinal perspective, Alfie continues to tolerate naso-jejunal (feeding into his small bowel instead of his stomach to avoid problems from gastro-oesophageal reflux) feeding without any vomiting. He is putting on weight and is growing as expected for his age. Alfie is entirely fed by the nasojejunal tube. He is unable to swallow. He currently does not show any signs/evidence of gastroesophageal reflux. All of his medications are administered via the nasojejunal tube. From a urological perspective Alfie has had a number of urinary tract infections which have been treated with antibiotics. He continues on prophylactic Trimethoprim to prevent further urinary tract infections. Alfie has not developed any contractures (joint stiffness) or evidence for scoliosis (curvature of his spine). Whilst it is possible that he might develop contractures or scoliosis in the future I think this is unlikely in view of his underlying severely reduced muscle tone and lack of movements.

Alfie does not show any visual behaviour suggesting a most severe visual impairment (blindness) although the full extent of this is impossible to determine as Alfie is unable to communicate. Alfie does not show any evidence of response to auditory stimuli (noise). Whilst there is no reason to believe that Alfie's inner ears are dysfunctional, the pathways and cortical centres that are required to process auditory information transmitted from the inner ear to the cortex are likely to be dysfunctional. Alfie is likely to have severe hearing impairment and is possibly deaf. This means, in his case, that his brain cannot interpret sounds entering his ear, rather than sound doesn't get past his ear. Alfie is unlikely to be able to tell/ interpret auditory stimuli i.e. reassuring voices or general noise on the PICU.

Alfie is entirely unable to communicate with his environment. He will never develop any communication either verbally or with sign language.

Alfie has shown severe/profound developmental delay and has lost what skills he had acquired entirely. He will never make any developmental progress (gross motor, fine motor, vision, hearing, social, emotional). Alfie is not responding to any painful or uncomfortable stimuli other than with

seizures or with spinal reflexes to uncomfortable/painful peripheral stimuli. Due to his underlying neurological process it is highly unlikely that Alfie has any awareness of pain or discomfort and does not show any neurological signs that would suggest that he is in pain or discomfort such as increase of heart rate, blood pressure, respiratory rate to uncomfortable/painful stimuli. It is likely that the pathways that would usually transmit the stimuli are interrupted/dysfunctional making a cognitive awareness of pain unlikely. However, as Alfie is unable to communicate, 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 sensation I think it is unlikely that Alfie has any ability to be reassured by the voices and touch of his parents.

31. To all this must be added the fact that Alder Hey Children's Hospital is a recognised centre of excellence in tertiary neurology and neurosurgery. It is a well-equipped, new and extremely impressive hospital. It specialises in investigating and treating children with the most complex neurological disorders. The range of investigation that I have set out above has also to be considered in the context of the available facilities at this particular hospital, which can properly be said to hold world-class facilities.

The Directions Hearing

32. The application brought by the Trust was first considered by me in mid-December 2017. I ordered the case be listed expeditiously. Alfie had been the subject of on-going investigation in the context of dispute for many months and it was clear that the case had to be scrutinised by the Court. I ordered the case be listed on the 19 December 2017. The parents were, at that stage, represented by solicitors. A robust application, on paper, was made to adjourn the Directions Hearing by F's team. That application was entirely misconceived. It is manifest that the case required to be scrutinised by the Court. At the Hearing, though the parents' statements had not been filed, a timetable was drawn up, with the assistance of experienced Counsel who acted on their behalf. The parents were given ample opportunity to put those documents together. I extended the timescales in order that they would not have to worry about the preparing of documents over the Christmas period, indeed, I stressed in Court that they should not do so. That time, I recognised, was very important to them.

33. Counsel appearing on behalf of the parents made a further application to adjourn the Directions Hearing on the 19 December. I rejected that application, authorised the instruction of a further expert and set down the case for hearing. I emphasised that the proceedings should move at Alfie's own timescales and not be driven by the exigencies of the litigation. I also indicated, without any request being made, that this was a case in which I would visit Alfie at the hospital.

34. Shortly before this hearing began the Court received communication from F, advising that he had parted company with his solicitors and was unrepresented. F was directed to an alternative and highly respected firm of solicitors, convenient to his home, who would probably take up the case. That was not pursued and by the time this hearing began the

parents remained unrepresented. I formed the clear impression that F thought that this fact would determine, in his favour, his yet further application to adjourn. It was a miscalculation on his part. F told me that his and the mother's human rights to a fair trial would be breached if he was forced to go ahead. My very clear impression was that the father wanted to do everything in his power to buy time for his son. I do not criticise him, on the contrary he has my every sympathy but it is, I hope, evident from everything that I have set out above that Alfie required a decision to be taken.

35. Mr Mylonas QC, who appeared on behalf of the Trust, opposed F's application to adjourn. He was entirely correct to do so. In resisting the application he emphasised that the medical evidence did not allow us to assume that Alfie is free from pain. Further, it was submitted, the evidence pointed compellingly towards futility of treatment. The parents had instructed experts of their own to advise them on the issues. During the course of the dispute the parents have engaged the services of no fewer than six different firms of lawyers. I agreed with Mr Mylonas that an adjournment was entirely irreconcilable with Alfie's best interests. That said, I should record that the Child's Guardian, represented by her solicitor Ms Carew, declared herself to be "probably neutral". I will make no comment on that.

36. I indicated to F that if I felt him to be under any disadvantage during the course of the Hearing he could restore his application to be represented. In the event, as anybody sitting in Court would immediately recognise, F's presentation of his case was extraordinarily impressive. His knowledge of the paperwork and the medical records was prodigious. His understanding of the functioning of the brain and his exploration of competing hypothesis was remarkable. At one point in the evidence when he had asked a question of particular complexity I asked him if somebody had been providing the questions for him. He told me, entirely convincingly, that he had written it out a moment or two before. His uncle, sitting next to him, confirmed it. F left school at 16. He served an apprenticeship as a plasterer. It says much about his commitment to his son and the time and energy he has directed to this case that he has absorbed the issues so completely and intelligently. He believes passionately that his view of Alfie's future is the correct one. As I said during the course of the evidence it can only be in Alfie's interest for all the available theories to be evaluated. On this premise therefore Alfie could have had no more articulate voice on his behalf than his father's in this Court room.

The Father's case

37. F's case is not entirely easy to state. His core dilemma, from which he struggles to escape, is that whilst he recognises and understands fully that the weight of the evidence spells out the futility of Alfie's situation he is, as a father, unable to relinquish hope. This is to my mind entirely understandable. It is a facet of F's grief. In consequence, there is often a tension in the logic of his position. His personal conflict emerges in its starkest form in his attitude to the Alder Hey Hospital. Sometimes F is fulsome and generous in his tributes to the doctors and medical staff, on other occasions his criticisms are vituperative. This tension resonates in his approach to the medical evidence. It is, I think, no coincidence that F, whose primary position is that "no stone should be left unturned", was resistant to the final MRI scan being undertaken. F, in my judgment, knew all too well, in the light of the earlier scans, what the latest MRI scan might reveal and, again for entirely understandable reasons, could not bear to confront it. As the Judge I did not have that

option, for the reasons that I have set out. It was shortly after the final scan became available that F renewed his application for representation. I interpret that as a signal of his distress but not as an indicator of forensic vulnerability.

38. When confronting the MRI images of the brain which show the degeneration in particularly graphic form, F has repeatedly stated *"I accept that, me and Mum are not in denial."* This is delivered with a degree of indignation and it is a comment that F has made on several occasions. Because it has been repeated in this way I have given it a great deal of thought, not least because nobody at this hearing has, at least overtly, suggested they are. I have formed the view that F understands entirely what the significance of these scans is. Time and again in his evidence he avoided confronting them. Though conscious of repeating myself here I do wish to stress again that I entirely understand F's dilemma.

39. All this leads F to cast around for alternative hypothesis. He has done his research well. He explores the possibility of an episode of silent aspiration of food, raised intracranial pressure, the possibility of an hypoxic incident and hydrocephalus. None of these is consistent with neurodegeneration. Moreover, as Dr R has repeatedly emphasised the volume of the brain has not expanded, brain tissue has been replaced in equal measure with a combination of water and CSF.

40. F presses for Alfie to be permitted to travel to the BG hospital (Rome) and provided with a tracheostomy and PEG feeding. He argues, if that proffers no solution, there should be a further transfer to the Munich hospital. If that too fails F says that Alfie should be allowed home to die *"when he decides to"*. In support of this F places reliance on the BG report dated 12.09.2017. I have referred to the analysis in the BG report above but notwithstanding their conclusions, they proffer a treatment plan which is very different to that advanced by the Trust. It is set out in the following extract from their report:

> *"It is therefore possible that a prolonged ventilator support, with surgical tracheostomy should be performed. Feeding and hydration are artificially provided through a nasogastric tube since several months, a clear indication for a gastrostomy is evident. Renal and liver functions seemed normal. Alfie appeared to be very well cared and despite eight months of ICU admission he did not present skin lesions due to posture*
>
> *During clinical evaluation there were epileptic seizures induced by propreoseptiv stimuli and associated with neurovegetative symptoms as cardiac rhythm and blood pressure disfunctions. This finding might affect a possible commute. A hypothetical transfer might be done from the patients bed to ambulance, to airport and subsequent ambulance or helicopter to the final destination. It is possible that during the travel Alfie may present continuous seizures due to stimulations related to the transportation and flight; those seizures might induce further damage to brain, being the whole procedure of transportation at risk."*

Some allowance has to be made here for the fact that the document is translated from Italian. I am satisfied however that there is no compromise of the document's cogency and nobody has suggested otherwise

41. Further support is found by F in the recommendations of Professor Haas. Again, at risk of over-burdening this judgment, I propose to set these out in full. These conclusions must be read in the context of my earlier analysis of Professor Haas's reasoning. He embarks upon his recommendations with this significant prefacing paragraph which because I consider it to be so key to the issues bears repetition:

> *"Based on the extensive testing already performed, I do agree with the medical teams involved that there are no useful tests that may be performed to improve Alfie's condition. The genetic testing (i.e. whole genome sequencing) is performed by blood sampling and without any risks for Alfie. These tests may in certain cases be beneficial to delineate a new rare disease as pointed out by the doctors of the Bambino Gesu Hospital. To the best of my knowledge these test have - even if a new disease is found - never been able to cure a patient with a similar disease pattern as Alfie shows."*

42. The following paragraphs from the report form the foundation of F's case:

> *"14. Regarding the potential transport of Alfie outside the hospital, it is clear for me that Alfie can be transported safely around the world at any place without any major risks for him. The objections of the managing team at Alder Hey are for me not understandable and without any reasonable medical basis (How can you opt for an extubation and thereby death but object a transport somewhere else as risky ?). In the same way I cannot understand the objection of the doctors at the Bambino Gesu Hospital. It seems evident for me that these statement, that Alfie may not be fit to fly or a transport would be extremely dangerous are arguments based on nonmedical reasons. Based on my assessment 1 can offer a medical transport certificate for Alfie wherever this is necessary - even directly to the Vatican (if financial support is granted)."*

> *"15. If Alfie would be transferred to our hospital, our management plan would include an estimated 14 days stay at our PICU including a tracheostomy and PEG insertion, a repeat EEG monitoring and MRI of the brain, equipment with a home ventilation system including training of the parents and a dedicated neuropaediatruic assessment and potentially additional genetic testing. Based on the German hospital payment system these estimated costs would be about 65.000,- €uro for the 14 days including surgery. Additional cost offers can be obtained for transport and home ventilation equipment".*

43. Professor Haas proffers this summary of his own perspective as to Alfie's best interests:

> *"16. To summarize this young boy Alfie is at the best of my knowledge unfortunately suffering from a severe, very likely progressive neurological disorder that will ultimately lead to his death. In agreement with the statements of his medical team I have difficulties to believe of any cure for this child. It is however unclear how many time he will be able to share with his parents. Apparently he has so far lived longer than initially projected. Withdrawing of treatment will immediately lead to his death and this can certainly not be in his interest. It is clear that in his best interest there should be a possibility for Alfie to live the possibly short rest of his life in dignity together with his family if this is the wish of his parents at home, which I believe is the best for him, outside a hospital or in a hospice or other form of caring institution. A dedicated neurological rehabilitation institution may be of additional benefit because there may well be other*

treatment and stimulation therapies I am not aware of".

44. Professor Haas was instructed by these parents to assist them and the Court on the basis of his experience and expertise, which is evidently considerable. It is no part of his function however to utilise the case as a platform for his own personal beliefs. I found the following concluding paragraph to be inflammatory and inappropriate, not least because the views expressed bear no relationship to and do not engage with the facts of this case. It would not be appropriate to edit them out of this judgment and for that reason only I set them out. I will address them below.

> *"Because of our history in Germany, we've 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 uncertainty of the feelings of the child, as in this case".*

45. The assumption of BG and Professor Haas is that the short note provided by Dr Hubner of the 'Pediatric Air Ambulance' could be relied on. Whilst that is a perfectly reasonable assumption to have made I regret to say that I have been unable to. Dr Hubner gave evidence and was cross-examined by Mr Mylonas. He accepted that he had gone to the Alder Hey Hospital in a clandestine manner, posing as a friend of the family. He agreed with Mr Mylonas that he had deliberately withheld his professional status from the doctors and staff. He told me that he had never done that before. I am at least relieved to hear that. It is corrosive of the bonds of professional trust and co-operation which are intrinsic to good medical practice and indispensible in a case of this kind. Further, it emerged that Dr Hubner had provided a statement directly to the father and to his solicitors. This had not been filed in these proceedings but it was produced at my request. The statement began with an assertion by Dr Hubner that he had seen all of Alfie's files. He accepted in evidence that this was not the case. In fact, he has seen very little. I emphasise that the statement contained a Declaration of Truth. Perhaps most alarmingly, Dr Hubner's travel plan for Alfie, set out an anticonvulsant medical regime which, on the basis of Alder Hey's experience with Alfie would have been ineffective and inappropriate. In particular the Midazolam proposed by Dr Hubner was entirely contra indicated by his medical history. Dr Hubner also told Mr Mylonas that he had not used the Air Ambulance for the purposes suggested here in cases where patients were dying. 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. Mr Mylonas makes the point that he seemed not to recognise the extent and significance of his shortcomings in his evidence. I agree.

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:

3 .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."

50. MacDonald J reviewed the authorities and distilled the principles to be applied very recently in **Kings College Hospital Foundation Trust v Haastrup [2018] EWHC 127 (Fam).** Though extremely helpful, it is unnecessary for me to reprise that exercise here.

51. 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 intrinsic value, however tenuous or vestigial it's 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 alluded and which collectively illuminate where Alfie's best interests lie.

52. Mr Mylonas presented a document to the parties which I permitted to be filed within the proceedings. The position of the Roman Catholic Church is sometimes characterised inaccurately in cases concerning these difficult ethical issues. Mr Mylonas's document is an open letter, by His Holiness Pope Francis to the President of the Pontifical Academy for Life, dated November 2017. In his message Pope Francis called for *"greater wisdom"* in striking a balance between medical efforts to prolong life and the responsible decision to withhold treatment when death becomes inevitable. His letter identifies that not adopting or suspending disproportionate measures can avoid over-zealous treatment. I would not presume to add any gloss to the following extracts:

"Your meeting will address questions dealing with the end of earthly life. They are questions that have always challenged humanity, but that today take on new forms by reason of increased knowledge and the development of new technical tools. The growing therapeutic capabilities of medical science have made it possible to eliminate many diseases, to improve health and to prolong people's life span. While these developments have proved quite positive, it has also become possible nowadays to extend life by means that were inconceivable in the past. Surgery and other medical interventions have become ever more effective, but they are not always beneficial: they can sustain, or even replace, failing vital functions, but that is not the same as promoting health. Greater wisdom is called for today, because of the temptation to insist on treatments that have powerful effects on the body, yet at times do not serve the integral good of the person. Some sixty years ago, Pope Pius XII, in a memorable address to anaesthesiologists and intensive care specialists, stated that there is no obligation to have recourse in all circumstances to every possible remedy and that, in some specific cases, it is permissible to refrain from their use (cf. AAS XLIX [1957], 1027-1033). Consequently, it is morally licit 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" (cf. CONGREGATION FOR THE DOCTRINE OF THE FAITH, Declaration on

> Euthanasia*, 5 May 1980, IV: AAS LXXII [1980], 542-552). The specific element of this criterion is that it considers "the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources" (ibid.). It thus makes possible a decision that is morally qualified as withdrawal of "overzealous treatment. Such a decision responsibly acknowledges the limitations of our mortality, once it becomes clear that opposition to it is futile. "Here one does not will to cause death; one's inability to impede it is merely accepted" (*Catechism of the Catholic Church*, No. 2278). This difference of perspective restores humanity to the accompaniment of the dying, while not attempting to justify the suppression of the living. It is clear that not adopting, or else suspending, disproportionate measures, means avoiding overzealous 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 a 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 befitting human dignity. In this process, the patient has the primary role. The* Catechism of the Catholic Church *makes this clear: "The decisions should be made by the patient if he is competent and able" (loc. cit.). The patient, first and foremost, has the right, obviously in dialogue with medical professionals, to evaluate a proposed treatment and to judge its actual proportionality in his or her concrete case, and necessarily refusing it if such proportionality is judged lacking. That evaluation is not easy to make in today's medical context, where the doctor-patient relationship has become increasingly fragmented and medical care involves any number of technological and organizational aspects."*

53. I regard the above as a comprehensive answer to the tendentious views expressed by Professor Haas. No further comment is required by me.

54. In her evidence the Guardian expressed her clear support for the Trust's application. Her view had been foreshadowed in her report. The evidence, she told me, had served ultimately to confirm her recommendation. She stated that in her view Alfie's life now lacks dignity and his best interests can only be met by withdrawing ventilation. This evidence from an experienced children's guardian requires to be considered very carefully. I have done so. With great respect to her I disagree with her view on Alfie's dignity. As I had promised the family I attended the PICU at Alder Hey to meet Alfie. I was greeted not merely with courtesy by the parents and a number of aunts and uncles but with a sincere and genuine warmth. I was and remain grateful to them. Alfie's pod in the unit is large, comfortable and he is surrounded by some of the world's most up-to-date technology. F was, in my presence, assiduous to Alfie's care. He is entirely besotted with his son. M, both parents agree, is far less involved in Alfie's practical care and less confident. Her contribution, in my assessment, is of an entirely different complexion. She has, if I may say so, a zany and delightful sense of humour entirely free from self-regard or pomposity. Her love for her partner and her son was obvious. The atmosphere around Alfie was peaceful, dignified and though some might find it surprising for me to say so, very happy.

The primary engine for all this is Alfie's mum.

55. Alfie's bed is festooned with toys. His walls are plastered with photographs and his many supporters have delivered a variety of football shirts to him. One, in particular, was signed by the entire Everton squad specifically for him.

56. Supporting all this is the diligent professionalism of some truly remarkable doctors and the warm and compassionate energy of the nurses whose concern and compassion is almost tangible. All this creates an environment which inherently conveys dignity to Alfie himself. In my judgment his life has true dignity. The far more challenging question is whether and if so how that can be maintained.

Conclusions

57. There emerge a number of key points in the evidence which now require to be identified. Most striking is the indisputable fact that Alfie's brain has been devastated by progressive degeneration. The MRI scans, as interpreted, are compelling. The thalami, which regulate the pathways of the brain, have entirely disappeared. This, I remind myself, controls the stimuli to the most basic sensory functions. Alfie has lost the capacity to hear, see, smell or respond to touch, other than reflexively. 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.

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.

59. Though F cleaves to the need for a diagnosis i.e. to understand what caused Alfie's condition, there are no more tests which can now sensibly be undertaken. Indeed, even if some were identified they would be of no use to Alfie. The brain does not regenerate. As

Dr M says a "label will not help Alfie now".

60. Whilst I have, for the reasons stated, rejected the evidence of Dr Hubner, I do not exclude the possibility that travel by Air Ambulance may remain a theoretical option. It requires to be considered however in the context of the matters above and one further important consideration. All agree that it is unsafe to discount the possibility that Alfie continues to experience pain, particularly surrounding his convulsions. The evidence points to this being unlikely but certainly, it can not be excluded.

61. Alongside all this it must be remembered that Alfie can not sustain life on his own. It is the ventilator that has been keeping him alive for many months, he is unable to sustain his own respiratory effort.

62. All this drives me reluctantly and sadly to one clear conclusion. Properly analysed, Alfie's need now is for good quality palliative care. By this I mean care which will keep him as comfortable as possible at the last stage of his life. He requires peace, quiet and privacy in order that he may conclude his life, as he has lived it, with dignity.

63. The plans to take him to Italy have to be evaluated against this analysis of his needs. There are obvious challenges. Away from the intensive care provided by Alder Hey PICU, Alfie is inevitably more vulnerable, not least to infection. The maintenance of his anticonvulsant regime, which is, in itself, of limited effect, risks being compromised in travel. The journey, self-evidently will be burdensome. Nobody would wish Alfie to die in transit.

64. All of this might be worth risking if there were any prospect of treatment, there is none. For this reason the alternative advanced by the father is irreconcilable with Alfie's best interests. F continues to struggle to accept that it is palliation not treatment that is all that can now be offered to his son.

65. In this judgment I have referred predominately to F who has been the advocate for both parents. I should make it very clear that M is in full support of F. She chose not to give evidence and I entirely respect her decision, nor do I draw any adverse inference.

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. I hope they will take the time to read this judgment and to reflect upon my analysis.

67. I should add by way of Post Script my thanks to Mr Mylonas. His presentation of this case has been assiduously fair and balanced throughout. His cross-examination of F was skilful, sensitive and kind. F paid a similar tribute at the conclusion of the case which I observed at the time and take this opportunity to reiterate, says a great deal about both of them.