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Case No: FD18P00658

Neutral Citation Number: [2018] EWHC 2750 (Fam)

IN THE HIGH COURT OF JUSTICE

FAMILY DIVISION

IN THE MATTER OF THE SENIOR COURTS ACT 1981

IN THE MATTER OF C (An Infant)

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 17/10/2018

Before:

MS JUSTICE RUSSELL

Between:

AN NHS TRUST	<u>Applicant</u>
- and -	
A & B	<u>1st & 2nd</u>
and	<u>Respondents</u>
C	
	<u>3rd Respondent</u>

Ms Sophia Roper (instructed by DAC Beachcroft LLP) for the **Applicant NHS Trust**
Ms Nicola Greaney (instructed by Irwin Mitchell LLP) for the **1st and 2nd Respondents**
Miss Shabana Jaffar (Cafcass Legal) solicitor for the **3rd Respondent through his Guardian,**
Kay Demery

Hearing dates: 12th October 2018

Judgment

The Honourable Ms Justice Russell DBE:

Introduction & background

1. The court is concerned with the medical treatment of an infant “C” who is just two months old. He is the much loved first child of his parents “A” and “B” (the 1st and 2nd Respondents). Antenatal ultrasound scans detected evidence of severe brain abnormality or malformation of his brain and confirmed the presence of a severe cortical migration defect consistent with lissencephaly/pachygryria. He was in poor condition at birth with Apgar scores of 2 at 1 minute, 3 at 5 minutes and 5 at 10 minutes; he was noted to be very oedematous, he had a low heart rate of around 60bmp with no respiratory effort, he was extremely floppy. He was intubated and placed on Neonatal Intensive Care (NICU); he has since been transferred to the high dependency unit (HDU). In addition, C has dysmorphic features including microcephaly, rectal prolapse, a form of diaphragmatic hernia, bilateral fixed talipes with “rocker bottom feet” and overlapping 3rd and 4th fingers.
2. To quote from the medical report prepared on behalf of the 1st and 2nd respondents by Dr Playfor (Consultant Paediatric Intensivist) “[C’s] main problem has been persistent and refractory epileptic seizures. These have always been associated with bradycardia, apnoea and oxygen desaturation, although the severity of the apnoeas and bradycardias have increased significantly in the last 2-3 weeks.” The almost continuous seizures are caused by severe brain abnormality
3. Since his transfer to the HDU hospital records suggest that C’s seizures have deteriorated and become more frequent and prolonged and associated with more profound episodes of apnoea, bradycardia and oxygen desaturation. In a concerted effort to reduce his seizures C has been given trials with multiple anti-epileptic drugs including phenobarbitone, phenytoin, midazolam, carbamazepine, sodium valproate, levetiracetam and topiramate. This latter medication was tried following the recommendation of Dr Rittey (Consultant Paediatric Neurologist) who had given a second opinion to the Trust (report dated 4th October 2018). C is currently on treatment with carbamazepine, vigabatrin and pyridoxal-5-phosphate. He is artificially fed through a naso-jejunal tube; but has had two tubes introduced, one through each nostril, the other being a naso-gastric tube.
4. There is no medical dispute as to C’s condition, he is a profoundly disabled child with severe lissencephaly. There is no available treatment for his underlying brain abnormality and his life-expectancy is less than one year; as Dr Rittey said in his report death for C is inevitable. His death can be imminent, or it can be delayed. His treating physicians Dr E (Consultant Paediatrician) and Dr F (Consultant Paediatric Neurologist) who both gave oral evidence, along with Dr S (Consultant Paediatrician) and Dr N (Consultant in Paediatric Intensive Care Medicine) also of the NHS Trust and both Dr Rittey and Dr Playfor, who are both independent of the Trust all concur that to continue repeated bag and mask ventilation and cardio-pulmonary resuscitation (CPR) to delay death does not confer any overall benefit as there is no reasonable prospect of seizure control.
5. The NHS Trust (the applicant) responsible for his treatment has made an application for a declaration that it would be lawful and in the best interests of the infant C for him a) not to be treated with intubation or mechanical ventilation; and b) not be to

treated with any resuscitative measures including cardiac massage and bag and mask ventilation, and that treatment be limited to palliative care; limiting therapeutic interventions to those that make him more comfortable and relieve his stress and pain. His parents, entirely understandably, wish to prolong C's life and to continue with bag-valve-mask ventilation and CPR with chest compression. They want him to be given an alternative medication, zonisamide, to attempt to treat his epilepsy and had sought that adrenaline be administered by the insertion of intra-osseous needles but, during the currency of the trial they withdrew their insistence on the use of adrenaline.

C's medical history

6. The severity of this infant's brain abnormality was apparent immediately at birth; within the first few hours of life C failed to demonstrate any spontaneous movements and began to show abnormal movements of his limbs with increased muscle tone. He developed myoclonic jerks, spasms and eye twitching episodes which were associated with oxygen desaturation. On cerebral function monitoring these abnormal movements were seen to be associated with abnormalities suggestive of epileptic seizures. He commenced treatment with phenobarbitone and a midazolam infusion. What was recorded on his initial electroencephalogram (EEG), which was carried out when C was 2 days old, was of extremely low amplitude, with some extremely low amplitude rhythmic activity seen along with almost continuous right frontal repetitive discharges which continued throughout the entire recording.
7. Such was his condition C was mechanically ventilated for the first two weeks of his life and was extubated on 25th August 2018 but worsening blood gases and increasing oxygen requirements led to him being reintubated 48 hours later. Following treatment for a chest infection he was finally extubated on 10th September 2018 onto Continuous Positive Airway Pressure (CPAP) for one day after which he was managed on high flow humidified oxygen via the Vapotherm device; which continues as C still has a significant oxygen requirement: 7 litres/min via the Vapotherm device with 45-50% inspired oxygen. His latest chest x-ray demonstrates widespread patchy consolidation throughout both lung fields, especially the right.
8. On 21st August 2018 an MRI brain scan was performed which was reported as showing "*Diffuse cortical migration abnormality - lissencephaly-pachygryria there is a nodular (almost cobblestone) appearance to the cortex anteriorly. No discernible myelin within the posterior limb of the internal capsules. Clear delineation of the basal ganglia structures is limited. The midbrain is thinned. There is a modest volume pontine eminence. Slight kinking of the cervico-medullary junction. There is a midline pituitary and infundibulum. There is a corpus callosum. Ventriculomegaly although without overt hydrocephalus. Hypertelorism. Normal appearances of the orbital globes per se. Cortical high T1 signal within the parietal occipital regions bilaterally – possible micro-haemorrhagic or micro-calcific change – although this is not convincingly represented on the SWI imaging. No diffusion abnormality. I do wonder whether there may be cerebellar polymicrogyria. Preserved vermian volume. Comment: Microcephaly with a cobblestone lissencephaly. Aetiological considerations include a congenital muscular dystrophy or tubulinopathy. RELN [sic] mutation (eg Norman-Roberts) although clearly other genetic mutations associated with lissencephaly should be considered*".

9. A second EEG was performed on 26th August 2018, recording several episodes of mouth twitching. The EEG remained of extremely low amplitude with moderate artefact. Frequent episodes comprising build-up of rhythmic activity with periodic and repetitive sharp discharges were seen over the frontal and central channels bilaterally. These were self-terminating and were not associated clinical changes. On stimulation he became unsettled and his face turned red with some upper limb movements seen. No significant EEG abnormality was seen during the mouth twitching episodes. The EEG was felt to be consistent with a diffuse and severe cortical pathology and it was noted that there were frequent electrographic seizures.
10. The third EEG was performed on 26th September 2018; it recorded frequent mouth, head and limb twitching movements, sometimes associated with oxygen desaturation. His background EEG remained of low amplitude with mixed frequency rhythms. There was frequent sharp/spikier activity that appeared to be quasi-periodic (often followed by brief periods of attenuation). These were seen bilaterally and independently over either hemisphere. On a couple of occasions, the pattern appeared to evolve becoming faster and sharper, particularly over the right side suggestive of an epileptic seizure. The opinion was that he was having frequent generalised epileptic discharges associated with twitching movements of his head and mouth. At the time he was found to have focal periodic lateralised discharges on either the left or the right side, with several brief electrographic seizures recorded in the right hemisphere. The findings were reported to be indicative of frequent epileptic seizures some of which were subclinical. In plain words the baby was, and is, suffering virtually continuous seizures some of which are not apparent clinically.
11. As Dr F explained in her oral evidence to the court, these were very abnormal EEGs and that although EEGs can be difficult to interpret in babies, there was no evidence of normal activity. What was seen was evidence of continuous abnormal activity from different areas, and both sides of C's brain and that, when clinically observed, C appears to be almost continually fitting. C has continuous focal seizures, observed in his eyes, face and hands which stop for a few seconds and then continue. C also suffers atonic seizures during which his there is a stiffening of all his limbs and a resulting low level of oxygen affecting his heart rate; his whole body is stiff and he goes red in the face. As set out above, the EEGs show signs of electronic seizures or sub-clinical seizures which are not observed clinically but appear to be continuous.
12. C was transferred to the HDU on 19th September 2018, since when the medical records (according to Dr Playfor) suggest that his seizures have deteriorated and are becoming more frequent, more prolonged and associated with more profound episodes of apnoea, bradycardia and oxygen desaturation. C can desaturate very frequently, several times in each hour, and requires airway positioning, or jaw thrust, performed manually by medical staff (where the jaw is manually and forcefully pushed forward) which is likely to cause discomfort at best and pain at worst, along with supplementary oxygen administration. Around 10 to 20 seizures episodes are typically documented each day and around 2 to 20 episodes are associated with severe bradycardia and oxygen desaturation which requires bag-valve-mask ventilation and jaw thrust, usually for a period of 2 to 3 minutes. A period of 7 minutes of bag-valve-mask ventilation was required at around on 10th October 2018. C has also required several periods of full CPR, with chest compressions during these episodes; the last

episode was around 6th October 2018 and an asystolic cardiac arrest was documented in the medical records on 1st October 2018 requiring one and a half minutes of CPR.

13. The court was told that CPR necessitates the forceful compression of C's rib-cage to one to two thirds of its depth. Dr E said, and I accept, that the force required to perform CPR on an adult can often lead to the fracture of one or more ribs, and, that while a baby's rib cage is much more flexible it must cause trauma and considerable pain. CPR usually administered when a person is in cardiac arrest and therefore unable to feel the pain associated with compression; C is, however, conscious. Dr E, as C's consultant paediatrician, told the court about C's current condition. C had continued to fit in the twenty-four hours prior to the hearing, on at least three occasions he had required bag and mask ventilation, and the evening before had required chest compression (CPR).
14. I was told that C had been given antibiotics the previous day as the medical staff were concerned he might have developed a chest infection, but thankfully, his chest had since appeared clear and he did not have the high temperatures associated with infection. As previously referred to C remains on high-flow oxygen at the lowest setting and is, for the most part breathing spontaneously, so it would be possible, Dr E said, for C to be transferred to low-flow oxygen which could be administered at home or in a hospice. C has had to have a tube inserted through each nostril; one into the stomach and the second into the small bowel; this is because his diaphragm is compromised and his stomach is abnormally placed, there is a likelihood that if he were fed through his stomach he could aspirate, so he is fed directly to the small bowel to avoid regurgitation; and, because of the need to assist and better facilitate bag and mask ventilation, the contents of his stomach are aspirated through the N-G tube. C has had to be moved frequently to perform jaw-thrust, bag and mask and/or CPR; this has led to the tubes becoming dislodged, which would cause the baby discomfort and pain, additional pain and distress is caused when he has had to have the tubes replaced under x-ray. This had been required once or twice a day for the past few days.
15. Dr E told the court that when the bag and mask ventilation is performed it requires the mask to be placed very tightly firmly over the baby's mouth and nose at the same time as his jaw is pushed forward forcefully to allow for oxygen to be forced into the baby. The procedure will involve at least one or two medical staff and is uncomfortable and painful. To illustrate the extent of C's seizures numerically over the past week, it was reported by Dr E and Dr F, C had had 22 seizures on 4th October 2018 three of which had required bag and mask ventilation of between 2 and 4 minutes. On the 5th October he had 12 seizures, three of which required bag and mask ventilation (for around one minute). On 6th October he had 11 seizures, four requiring bag and mask ventilation of around 2 minutes. On 7th October he had 13 seizures, only one of which required bag and mask ventilation. On the 8th he had 12 seizures four of which required bag and mask of 2 minutes each. On 9th October he had had 19 seizures seventeen of which required bag and mask ventilation of between 1 and 2 minutes. On 10th until 12:00 hours C had had 11 seizures three of which required bag and mask ventilation of between 1 and 6 minutes. Since then and the hearing on 12th October C has had further seizures including one that required CPR and had required bag and mask ventilation on at least three occasions. This, as we have heard, led to further pain and discomfort when the naso-gastric and naso-jejunal tubes are dislodged and replaced.

16. C's medication. According to Dr Playfor's report C has had multiple trials with nine anti-convulsant drugs including Topiramate; this latter having been recommended by Dr Rittey who gave a second, independent, opinion; in it he said C "*has a an extremely severe cortical migration abnormality which falls within the spectrum of lissencephaly. This is at the most severe end of this spectrum of disorders. As a consequence of this [C] will have profound developmental impairment with profound learning disability, a four-limb motor disorder and cortical visual impairment. In addition, he is at risk of significant medical complications such as epilepsy, recurrent respiratory infection, gut dysmotility etc. [C] also has associated somatic malformations with rectal prolapse and diaphragmatic hernia...The key issue, however, is the nature and severity of [C's] epilepsy. This is characterised by extremely serious epileptic seizures which are associated with severe apnoea, desaturation and bradycardia. I have witnessed one of these seizures and was impressed by the severity of the seizure and the difficulty of managing it. These seizures have proved resistant to multiple appropriate anti-epileptic drugs as outlined above [in the report]*" Nonetheless, Dr Rittey went on to say that, while he thought it unlikely that C would respond to topiramate, "*I am of the view that it is worth giving him a trial of the drug as a final option for managing his epilepsy.*"
17. The topiramate was tried over a period starting on 3rd October up to and including 6th October 2018. It did not prove to be effective; there was no change in the frequency of seizures. The treating physicians then treated C with a trial period of 24 hours of pyridoxal-5-phosphate on the basis that there was one case in the literature (not a case of lissencephaly) in which it had proved successful in stopping seizures. It was thought it was very unlikely that the seizures would stop and sadly that proved to be the case. There is no evidence before the court that the trial of topiramate was not completed nor that the drug was incorrectly administered, as was previously argued by C's mother. As observed by Drs E and F C's epilepsy has proved truly refractory (resistant to treatment). Although the trial of topiramate proved to be unsuccessful, and notwithstanding this lack of success, his mother, in her oral evidence asked that the court should order another trial of a 10th anti-epileptic medication, zonisamide, and if that has no effect to order that there should be a further trial of topiramate. She also spoke of the use of cannabidiol (cannabis extract); but the court understands it's use is no longer pursued.
18. The medical evidence regarding these two drugs (zonisamide and cannabidiol) was given by Dr F as a consultant neurologist. The court was given two papers relied on by the respondent parents which concerned the use of zonisamide on older children (the youngest was eighteen months) none of whom suffered a condition corresponding to C's. Dr F explained that zonisamide had been used in Japan for many years for the treatment of children over a year old but that in the UK topiramate is used in preference. She explained in detail that both the drugs worked on the neurotransmitter systems to reduce or stop seizures, in particular GABAergic and glutamate systems but not in the same way; the drugs are similar but not the same. The use of zonisamide in very young children carries a substantial risk of side-effects, including stopping sweating which in turn leads to overheating, which could be fatal, and severe allergic reactions.
19. The strength of the drug zonisamide means that it requires that the dosage is built up slowly over a period of weeks. Dr F told the court that she did not think that such a

trial was sensible at all, there was little likelihood of it working and there would be no benefit to C. Objectively, the additional trial of a drug so similar to that which was tried on the advice of the consultant who provided the second opinion, and which proved unsuccessful, must be contra-indicated. Dr F had no experience of the use of the drug in a child. There is no evidence before this court that is capable of supporting an additional and prolonged trial of a drug which is not only similar to one which has already been tried (and failed) but for which there is no data available in respect of very young infants and, in particular, those with a condition as severe as C's. In respect of cannabidiol Dr F told the court that it is used for two specific conditions in older children (Dravet Syndrome and Lennox-Gastaut Syndrome) neither of which C suffers from, was not suitable for use on C and that the associated side-effects would be detrimental to his health.

20. At the core of this case is the fact, which is not disputed, that C has severe brain malformation which is life-limiting. All the medical opinion is that C's life expectancy is under one year; this is accepted by C's parents. There is no surgical procedure which can resolve, or even begin to resolve, the abnormality or change the underlying problem which has dramatically shortened his life, the bradycardia (abnormally slow heart) apnoea (cessation of breathing) and oxygen desaturation have increased dramatically over the past two to three weeks. According to Dr Playfor it is most likely that the abnormality is genetic, and C suffers from other congenital abnormalities too, he has a form of diaphragmatic hernia which means there is bowel protruding through the diaphragm, lying beneath the right lung. C's lungs have an abnormal appearance on x-ray, he has a high oxygen requirement and it is Dr Playfor's opinion that C is at "*very high risk of developing periods of respiratory failure in future*". Dr Playfor writes: "*Taking the entire clinical picture into consideration it is my opinion that C will have a significantly shortened life-span and may die during infancy as the result of seizures, pneumonia or sepsis.*"
21. C's growth and development is not, in any sense, comparable with that which would be usually be expected of an infant of his age. Although he does show some sign of head growth since birth, his weight now is essentially static (3.51kg on 7th October and 3.5kg on 10th October 2018); C is a very small, profoundly vulnerable baby who has only been able to survive this long with continuous medical intervention. It is hard to reconcile this picture with his mother's assertion in her statement that C has "*grown and developed in his own right*", but one can readily comprehend her need to say so.
22. Responsiveness and awareness. C's awareness of his surrounding and his ability to respond to stimuli has been the subject of some dispute. There is no observation or note to be found on any of C's hospital or other records, which were carefully reviewed by Dr Rittey or Dr Playfor, which suggests that he has ever shown the ability to visually fix on, or follow, objects in the environment, as would be expected of an infant of his age. C's mother, A, who has remained at his side since birth and is undoubtedly highly devoted to him, is clear that he responds to his father's voice and to A when she bends over him or puts her face close to his; the former was observed by Dr Rittey during his examination of C, but had not been observed by Dr Playfor and the physicians treating C. C's mother told me he responds by smiling and that he enjoys and is comforted by a mobile above his cot, but Dr F gave evidence that he

does not smile (expected in an infant by around six weeks) and that he does not fix or follow even on light.

23. Nonetheless, there is no dispute that C has some limited awareness of his surroundings and I accept, as Dr Rittey said, that C is aware of both positive and negative stimuli. Dr Rittey's description of a seizure he observed is telling, "*[it] began with twitching of the right side of his tongue which became bilateral and then spread to his face. He developed tonic flexion, becoming rigid. He rapidly went blue and oxygen saturation dropped extremely fast. He became bradycardic. He required bagging – it was clearly extremely difficult [to] achieve adequate jaw thrust to allow air entry and was not until the tonic phase began to ease off that effective bag saturation could be achieved.*"
24. While it is accepted as observed by Dr Rittey that C has some awareness of positive stimuli and receives much in the way of positive input from his family it follows that C must be aware of negative stimuli; and that the repeated bagging, CPR, and inevitable interventions such as the replacement of tubes, cannulation, suction are clearly negative stimuli and are likely to be painful, distressing and uncomfortable. To quote from Dr Playfor's report "*[C] experiences significant burdens as a result of his disease with very frequent seizure activity and this is also associated with significant bradycardia and oxygen desaturation to levels which are distressing in older children who are able to report their experience: Clinically significant bradycardia and oxygen desaturation is typically associated with feelings of distress, shortness of breath, panic and a fear of impending death.*" Dr Playfor observed in his report that bag-valve-mask ventilation is usually described as uncomfortable by older children who can report their experience; it cannot be less so in a small and fragile baby.

Law

25. There is no dispute between the parties as to the law to be applied; the decision is one of best interests, each case is fact specific. The court is being asked by the applicant to make a declaration that it is lawful and in C's best interests to withhold certain treatment, for the baby not to be resuscitated and, instead, to be provided only with palliative care. C is separately represented by Cafcass Legal and has a court appointed guardian, who has "with a heavy heart" concluded that the declarations being sought by the NHS Trust are in C's best interests.
26. In principle, and in law, it is the responsibility of parents to make decisions on behalf of their child, including any consent to medical treatment or, as in this case agreeing for treatment to be withheld or withdrawn. When, as is the case with C, parents do not agree with the withholding or withdrawal of treatment considered by clinicians to be in the child's best interests, the court can intervene and overrule their refusal even if it could not be said to be unreasonable: *Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242. The principles and guidance as to how the court should exercise that authority was set down by the Court of Appeal in *Wyatt v Portsmouth NHS Trust* [2005] EWCA Civ 1181 [87], "*In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient (Re J). There is a strong presumption in favour of a course of action which will*

prolong life, but that presumption is not irrefutable (Re J) The term best interests encompasses medical, emotional and all other welfare issues (Re A). The court must conduct a balancing exercise in which all the relevant factors are weighed (Re J) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A)".

27. As the law is well established so there is no need in this judgment to set out a more extensive reference to authority and case law. A dispute has arisen between the NHS Trust and the parents of C and because of that the Trust applied to the court to make declarations, the court's jurisdiction can only be exercised in this case because C as an infant child, lacks the capacity to decide for himself. The test to be applied is an objective one to determine what is in the best interests of the C. Thus, when considering his best interests, I include C's medical, emotional, sensory perceptions (including his ability to give and, in C's case as a small baby, especially to receive love and affection, his awareness of his surroundings, and his pain and suffering) and the human instinct to survive and prolong life. There is, and it has been long established, a very strong presumption that is attached to the prolongation of life because the human instinct and desire to survive is strong and so must be presumed to be so in the patient, even if that patient is an infant.
28. The strength of that presumption, expressed by Lord Donaldson of Lymington in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33, is not absolute, as he said; "*We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive."*"
29. As in all such cases, the courts' decision is wholly based on the specific facts of C's individual case. The views and opinions of the treating clinicians and medical professionals and the parents will be carefully taken into consideration. C's parents, particularly his mother who has barely left his side since he was born have spent a great deal of time with their child, so their views have particular value because they know C so well; but I have to keep in mind that the view of any parent is likely, and understandably, to be influenced by their own emotions, feelings and beliefs. I recognise that A and B hold to their faith and culture and have strongly felt views and take cognisance of the strength of their religious belief, but it is not determinative. The wishes and beliefs of any parent serve to inform and provide the court with an explanatory background as to the quality of the child's relationship with her or his parents and family but they are not necessarily relevant to an objective view of the best interests of the child.
30. I note too, the limitations of the court's powers as applied by MacDonald J in *Re Y (No 1)* [2015] EWHC1920 (Fam) at [34] of his judgment "*It is important to note that the court has no power to require doctors to carry out a medical procedure against their own professional judgment.*" Later he said [37], "*Whilst the right to life under Art 2 of the ECHR imposes a positive obligation to provide life sustaining treatment that obligation does not extend to providing such treatment if that treatment would be futile in nature and where responsible medical opinion is of the view that the*

treatment would not be in the best interests of the patient concerned (see R (Burke v The General Medical Council [2005] EWCA 1003).”

31. In the case of *Re A (A Child) [2016] EWCA Civ 759*, to which I have made reference above, the Court of Appeal confirmed the law in this area, while requiring great sensitivity and care, can be summed up in two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Foundation Trust v James [2013] UKSC67*, [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.*” At [39] she continued; “*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.*”

C’s Best Interests: the balance of benefits and burdens

32. In considering C’s case I have already set out some of burdens and the benefits for C above. I shall start to consider those benefits and burdens in the balance to reach a conclusion as to C’s best interests by looking at the positives. C’s guardian (in her position statement) and Dr Rittey both observed C on the ward with his parents. The guardian was able to see the high level of care provided by C’s parents and the hospital staff. The family ensure that C is never left without a family member on the ward and his mother spends most, if not all, of her time caring for him. The benefit to C, as a little baby, in receiving the love and affectionate care from his family is clear. C’s guardian described C as an attractive little baby who was beautifully dressed in a babygro. At the time of her visit to C a scan was being undertaken, while the probe was being used she observed C to grimace and his diaphragm was moving rapidly up and down; he appeared breathless, his eyes were closed, and he lips moved almost continuously. During the hour or so of her visit C’s oxygen levels fell and he required an oxygen mask to be applied on three occasions; the guardian saw C’s colour change and he legs coming up to his chest in seeming discomfort. C’s father gently stroked his head and removed secretions whilst keeping an eye on the monitor to assist the nurse. C’s father was gently speaking to his son and C’s eyes opened periodically.
33. The guardian was able to give the court an independent and objective view of C’s situation in hospital, as was Dr Rittey. Dr Rittey said that C lay largely immobile but that there were occasional twitching movements of his hands and he showed hip reflexion and abduction to stimulation; he had shown clear and repeated eye-opening to his father’s voice; “*this was clearly different to the eye-opening which occurs in association with the seizures and he did not show eye-opening to my voice, except on*

one brief occasion." His tone was generally reduced but increased on stimulation. C has extreme head lag on being pulled to sit, no other obvious neo-natal reflex response other than reflex movements to stimulation. I have already referred to C's seizure observed by Dr Rittey and that both he and Dr Playfor had observed he grimaced to supraorbital pressure.

34. C's mother says that C takes pleasure from his surroundings including comfort from the mobile he has above his head. He clearly is aware of, and reacts to, his father's voice. C's mother says that C grasps her finger if she puts it in his hand. I entirely accept this, but also accept that it is a primitive reflex present in new-borns and cannot be taken as evidence that he is aware of his mother or is holding on to her. It is easy to understand why A hopes it is the case. I accept Dr Rittey's report of C having random roving eye-movement, and his evidence, supported by Dr Playfor, that there was no evidence of visual fixation, in other words there is no evidence that he can focus and/or fix on any object. On the balance of evidence before this court C's awareness is extremely limited, but I am certain that he must derive some comfort and reassurance at a very basic level from being held by his mother, or other loving members of his family.
35. Against these benefits must be balanced the burdens and sadly, the evidence is that C has suffered, and continues to suffer, pain, discomfort and distress constantly and frequently every day of his short life. At all times C has an N-G tube in one nostril and N-J tube in the other, he has EEG wires attached to his tiny chest and an oxygen tube on his foot to measure oxygen levels, at the very least this will cause discomfort. His associated congenital abnormalities means he isn't even able to eat or suckle, nor will he ever be able to do so. He has the burden of very frequent seizures and as observed by Dr Playfor "*the extra-ordinary level of intervention which is currently being delivered to [C] is not part of a therapeutic plan with any realistic prospect of improving his underlying condition, and is undoubtedly contributing to the burden of discomfort which he currently endures...It should be noted that the current situation with multiple daily episodes of bag-valve-mask ventilation and occasional CPR necessitates C being continuously monitored and cared for in a high dependency area by staff highly trained in advanced paediatric life support with the immediate availability of advanced resuscitation equipment. This prevents C spending time alone with his family and experiencing other more pleasant, non-clinical environments.*"
36. As I have already set out, C is daily and repeatedly subjected to the burdens of treatment associated with the frequent seizures he endures: but he also has the burdens of constantly and repeatedly suffering significant bradycardia, apnoea and oxygen desaturation at levels that would be highly distressing to anyone able to report their experience; and are associated with feelings of distress, shortness of breath, panic and a fear of impending death, as described by Dr Playfor. The fear induced by breathlessness is atavistic and experienced by anyone, no matter how young or old, who is left gasping for breath; it would be unacceptable to overlook the likelihood that distress and even fear is inculcated in C by his constantly experiencing shortness of breath.
37. To that must be added the considerable burden of the repeated pain he suffers when he is subjected to jaw thrust, as observed by Dr Rittey, the use of bag and mask together with jaw thrust and the less frequent but still often repeated CPR. Each treatment, when objectively considered separately or in combination, brings with it

the burden of pain, discomfort and distress. Of the three the CPR would seem the most painful with the need for the use of considerable force and physical trauma to this already fragile and very vulnerable child. The court heard that the necessary force causes rib fracture in adults, it is highly likely, if not inevitable, that it has and would continue to cause bruising and trauma to C's rib cage and internal organs. It is not possible to have effective "gentle" CPR as suggested by A in her statement. C's parents wish CPR to continue to be performed; CPR has rightly described as an aggressive act as the chest is compressed with such force that ribs may be broken. This court is aware that this is not unknown when CPR is performed on infants.

38. The court must consider the purpose and likely outcome of the continuation of the use of bag and mask and CPR, which would be only to delay or put off C's inevitable death because C's condition is irreversible and untreatable. This continued intervention is ultimately futile and is highly likely to significantly increase C's suffering at his death as it is likely to lead to C spending his last minutes alive surrounded by medical and nursing staff instead of being comforted by the people who love him.
39. Both Dr Rittey and Dr Playfor referred to and considered the Guidelines of the Royal College of Paediatrics and Child Health (RCPCH) (2015) which provided an ethical and legal framework for making decisions to limit life-sustaining treatment in life limiting and life-threatening conditions in children. The RCPCH guidelines set out 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; 1) when life is limited in quantity; if treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:
 - A. Brain stem death, as determined by agreed professional criteria appropriately applied
 - B. Imminent death, where physiological deterioration is occurring irrespective of treatment
 - C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.
40. 2) When life is limited in quality; including situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself.
 - A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits
 - B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life
 - 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.

41. The third is the informed competent refusal of treatment which does not apply in C's case. It was Dr Playfor's opinion that C's "*clinical situation meets the following criteria: 1C; 'Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by life-sustaining therapy confers no overall benefit', 2A; 'Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits', and 2C; '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'.*"
42. Dr Rittey said in his report, "*it is clear that [C's] life is limited in quantity...I believe that death for [C] is inevitable, it may be imminent or it may be delayed...it [is] my opinion that continuing to attempt to delay death by repeatedly bagging him during seizures and undertaking CPR does not confer any overall benefit as there is no reasonable prospect of seizure control. Clearly this must take into account my suggestion of a short trial of topiramate. However, if this is ineffective I consider there to be no meaningful further option for seizure control for [C] this advice is consistent with RCPCH guidance section 1 para C.*" Dr Rittey went on to say "*...[C's] life, as it is currently, is significantly limited in quality. Although he does have some awareness of positive stimuli (and he receives many positive inputs from his family) he is similarly aware of negative stimuli. The repeated bagging, cardiac compression and inevitable interventions such as the replacement of PEJ tube, cannulation, suction etc. are likely to be both painful, distressing and uncomfortable. Continuing to resist the inevitability of [C's] death by repeatedly subjecting him to bag and mask ventilation and/or cardiac compression is a major burden for [C] ...since there is no meaningful prospect of seizure control [it does] not confer any long-term benefit.*"
43. Although Dr Rittey went on to say that C's condition did not cause him pain per se, this court could not agree that it did not cause him distress at the very least, as set out above. Dr Rittey considered, and it is the case, that the medical complications would require potentially painful interventions and that "*...striving officiously to resuscitate him from uncontrolled seizures is not in his best interest. I believe that the guidance provided in section 2 para [A] and C of the [RCPCH] document would support this position.*" On behalf of C's guardian, it was submitted that withholding the specific treatment set out in the application of the NHS Trust would be in C's best interests.

Conclusions

44. Drs Playfor and Rittey as independent clinicians and C's guardian and his legal representatives have all carefully considered the benefits to C of receiving the treatment that A and B want to prolong C's life or delay the inevitability of his death. The conclusion that the treatments will not restore health is aphoristic but true. C will not survive his condition and decisions made about his treatment by the physicians and medical professionals are made in that knowledge. Indeed, C's parents were made aware of C's brain severe abnormality and lack of development before he was born. Dr F explained to the court that while in utero C's brain abnormality meant that he had not moved about as normal and had affected the development and mobility of his limbs. Dr E spoke in his written and oral evidence of the great discomfort felt by him, and his colleagues, about the conflict with A about C's treatment and the concern felt about the continued use of bagging and CPR after the trial of topiramate had proved unsuccessful. There can be little doubt that the discomfort felt by the medical

professionals reflects their reluctance to continually inflict pain and distress to C. The court accepts that C's life expectancy is short but that there is no means by which it can be precisely or accurately predicted. The court is being asked to consider what is in this baby's best interests for the short time that is left to him.

45. C is loved by his parents and family, but he is also a child who has continually and repeatedly suffered pain and distress because of his condition and the medical intervention and treatment he has required. There is no evidence before the court that would suggest a positive outcome in a trial of a tenth anti-epileptic drug, zonisamide still less to support a second trial of the similar drug topiramate; as with the continued use of bag and mask and CPR, it would only be delaying the inevitable while subjecting C to further pain and distress as he continues to suffer many seizures each day. C's death is inevitable, and nothing can be done to stop it or reverse or treat his underlying condition. (See paragraphs 17 to 19 above.) It is the judgment of the court that C should be permitted to end his life in as comfortable, pain-free and comforted condition as it is possible to achieve.
46. It is understandable that C's parents, particularly his mother, want medical staff to persist with treatment and/or intervention an attempt to extend C's life but the court is objectively concerned with C's best interests and I am aware that to continue to intervene, to bag and mask and to carry out CPR is against the advice and wishes of C's treating physicians and his medical team for good reason and because they are aware that continued intervention and treatment will not address the cause of the frequent seizures suffered by C. This is a baby who has already suffered a great deal. I have endeavoured to consider C's situation from his perspective in as much as it is possible for any court to do so. The conclusion that I have reached is that it is in C's best interests for the court to make the declarations sought by the NHS Trust because the intervention and invasive treatments which his parents seek confer no real benefit and subject C to continuous, and ultimately futile, pain, suffering and distress; it follows that it is lawful for the treatments to be withheld.
47. This is my judgment.