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Case No: ZE 16C00811

Neutral Citation Number: [2017] EWHC 370 (Fam)

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
IN THE MATTER OF Section 31 of THE CHILDREN ACT 1989
AND IN THE MATTER OF THE SENIOR COURTS ACT 1981

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 24/02/2017

Before:

MS JUSTICE RUSSELL

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Between:

A LOCAL AUTHORITY	**Applicant (Care proceedings)**
and	
A NHS TRUST	**Intervener& Applicant (Inherent jurisdiction)**
and	
MC	**1st Respondent**
and	
FC	**2nd Respondent**
and	
C (A child by his guardian)	**3rd Respondent**

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Ms Frances Orchover (instructed by **the Local Authority Legal Department**) for the **Applicant (Care Proceedings)**
Ms Caroline Hallissey (instructed by **Daniel Freeman**) for the **Applicant (Inherent Jurisdiction proceedings)**
Ms Allison Munroe (instructed by **Coram Children's Legal Centre**) for the **1st Respondent**
Ms Joy Brereton (instructed by **Owen White Catlin**) for the **3rd Respondent**
Hearing dates: 8th February & 15th -16th February 2017

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Judgment

WARNING: section 97 Children Act 1989
This judgment is subject to reporting restrictions under statute and nothing is to be published which identifies or could lead to the identification of the subject child.

The Honourable Ms Justice Russell DBE:

Introduction

1. Within parallel care proceedings a NHS Trust (the Trust) applies for a declaration that it is lawful to withhold certain invasive treatment from the child who is the subject of both care proceedings and proceedings brought under the inherent jurisdiction. The child is C, now thirteen and a quarter years old.

2. C was born prematurely, at 24 weeks' gestation, on 5th November 2003. He is the subject of section 31 Children Act (CA) 1989 care proceedings issued by a Local Authority in November 2016 and of a subsequent oral application for declarations in respect of withholding medical treatment brought under the inherent jurisdiction of the High Court (pursuant to the Senior Courts Act 1981). His mother (MC) does not agree to treatment being withheld; nor does she agree to there being a care order made. C is separately represented through his children's guardian. He is presently subject to a s38 (CA) interim care order.

3. C suffers from multiple disabilities; he has severe four limb involvement spastic quadriplegia with athetoid cerebral palsy, global developmental delay, no vocal communication, curvature of the spine, epilepsy, very limited swallowing reflex and respiratory problems associated with his limited lung capacity and very limited respiratory reserve with chronic small aspiration into his lungs depleting his lung function. His lungs are damaged because of previous infections and he is susceptible to infection generally because he suffers chronic malnourishment. In addition, C has suffered from chronic severe acid reflux. C's epileptic symptomology includes involuntary movements and dystonic spasms. When distressed his tone heightens (he becomes stiff); this occurs when he is suctioned to remove secretions. His life expectancy is limited.

4. C has always lived with his mother apart from periods in hospital; and a short period when he was cared for by his maternal family in Romania when C and his mother had some difficulty in re-entering the UK.

Background to the proceedings

5. There have been chronic concerns about C being underweight and under-nourished which are well-documented and had previously led to him being fed through a naso-gastric tube (NG). He was fed by an NG tube until 2011 after which he was fed orally. In 2012 C was the subject of a child protection plan under the category of neglect; care proceedings were issued in October 2012. In April 2013 the local authority was granted permission to withdraw proceedings to enable further intervention with the family in co-operation with MC.

6. On 23rd February 2016 C was referred to W Hospital by his school because of concerns about his poor physical presentation. In March 2016 a NG was fitted to provide C with feed to supplement his oral intake of food. He was discharged on 5th April having had NG tube inserted; C gained weight during his admission to a weight of 21kg. On 14th April 2016 C was again placed on a Child Protection Plan under the category of neglect. On 9th May 2016 MC said that C had removed the NG tube; she resumed oral feeding and C's weight fell again. MC declined to consent to an NG tube re-insertion. In May and June 2016 MC cancelled arrangements to visit a Hospice for an assessment of C.

7. On 30th June 2016 C returned to school. On 20th July 2016 MC failed to take C to an appointment with Dr. M, C's treating consultant paediatric gastroenterologist who was in charge of the feeding clinic he attended. At some time between the middle of July to 12th September 2016 MC took C to Romania; she did not inform the local authority of this trip and so C was reported to police as missing person. On her return MC said that the NG feeding tube had "come out" and that she reverted to oral feeding. By 19th September 2016 C's school had advised MC not to bring him into school because of concerns regarding his weight and high tone (stiffness in his limbs).

8. On 5th October 2016 the NG tube was again re-inserted; mother says it came out due to vomiting. C was to be admitted to the R Hospital (RH - the NHS Trust hospital) for nutritional rehabilitation. On 12th October C attended the feeding clinic with his mother who refused to have the NG tube re-inserted.

The Applications

9. The local authority first became involved with C and his mother in 2005. There were previous care proceedings in 2012 which were withdrawn with the intention of being able to work in co-operation with MC. It is the local authority's case that these proceedings were issued because of *"increasing concerns about the mother's ability to co-operate with [C's] treatment plans, medication and feeding."* C's weight has been a long-term concern of medical professionals responsible for his care; his low weight leading to occasions when he has been admitted to hospital for feeding tubes to be put in place. The local authority contends that there is evidence of MC's difficulties in working with professionals over the years and her "disguised compliance". The local authority's case is that when discharged C should not return to the care of his mother but live in a specialist foster placement identified for him that can best meet his needs.

10. The Trust are seeking a declaration for a "ceiling of care" or that to withhold certain treatment would be lawful as it is in C's best interests to do so. It is their intention to put in place a *"redirection of management from life sustaining treatment to palliative"*. This would mean that all invasive treatment would be withheld and that only non-invasive interventions with the aim of improving C's quality of life should be continued, such as the provision of oxygen, some suctioning, peripheral IV antibiotics, physiotherapy, CPAP, analgesia and secretion control. The Trust say that their application is urgent, principally because C's condition fluctuates, and they seek an immediate order, a matter to which I shall return.

C's Background

11. C was born in the UK, at the Royal London Hospital. His mother MC is Romanian. They have spent time in Romania in 2007/8 and again in 2011. MC has sought to rely on some of the medical opinion and advice that she said she received in 2011 in respect of the extent of C's disabilities and, in particular his ability to swallow and ingest food orally.

12. His father FC is said to be living and working in London and has had some sporadic contact with his son. He has not taken part in these proceedings as neither the Trust or the local authority have been able to locate him, to serve him with notice of these proceedings. MC told me that she has attempted to contact FC on Facebook when C was taken into hospital; and that she had spoken to FC's brother.

13. C's mother MC is his principal carer and she has made him the centre of her life; because of his multiple disabilities and difficulties it has undoubtedly been a full time occupation and struggle for her, and she has had little, if any, personal support. Despite the many criticisms of her behaviour, and of some of the care she has given C, it is clear from his guardian's observations, and those of his care support worker in hospital, that C gains comfort from her presence and is happy when she is there. Unfortunately, MC finds it difficult to take accept and act on advice that she does not agree with, or which does not coincide with her view of what is best for C. During his last, and present, admission to hospital, since October 2016, as the result of MC not complying with medical and nursing advice she was supervised when on the ward with C; and her time on the ward restricted to between the hours of 09:00 and 18:00. This time was increased to 24 hours a day while C was in ICU.

Hospital Admission October 2016 to February 2017

14. On 12th October 2016, before the care proceedings were issued on 25th November, C was admitted to RH following a referral from Dr M (the consultant in charge of the feeding clinic) C attended. Dr M has seen C the week prior to his admission and had said that if he did not gain any weight the intervening week he should be admitted to hospital; the concern was that C was not receiving sufficient nourishment whilst in the care of his mother. He did not gain any weight so was admitted to hospital where he was under the care of Dr N, one of the three paediatric gastroenterologists who have rotating duties for the in-patient children. As Dr N is on sick leave another consultant Dr K, a locum consultant who had taken over responsibility for C from Dr N, gave oral evidence before me.

15. When admitted to hospital C's appearance was characterised as skeletal; in her oral evidence to me his mother accepted that he *"was very, very thin"*. He was considered to be suffering from malnutrition. It is a matter of common sense that any child who is malnourished is more susceptible to infection and illness, a child such as C is, of course, so much more vulnerable.

16. Once in hospital C was fed by several methods, at first he continued to be fed orally by his mother but as he was observed and reviewed by medical professionals including speech and language therapists (SALT) and dieticians it was eventually decided that he would have to be fed by (PEG-J) percutaneous endoscopic gastro-jejeunoscomy) tube.

17. At first the advice was that as thin fluids presented a risk of aspiration he should not be given tea or coffee or juice, but could still be given food orally. His malnourishment meant that he had to be given supplementary nutrition by tube. By the beginning of November 2016, and from their frequent observations, it was the opinion of the SALT specialists that C did not have the oral motor skills safely to eat and drink. MC, who was responsible for his feed was frequently in dispute with the hospital staff about feeding C; there can be no doubt, as can be seen from the history of this case set out above, that C's mother preferred to feed him orally. There continued to be difficulties in feeding C and he was not receiving sufficient nutrition.

18. On 15th November MC at first consented to and then withdrew her consent to a gastronomy, which would have enabled C to receive nutrition directly as he was unable to ingest food safely orally. SALT then recommended that he was fed directly through a tube inserted into his gut (through an NJ tube) and that he was not to be fed orally as it was not safe as his lack of ability to swallow compromised his safety (food or liquid would enter his lungs causing aspiration; in addition to spastic quadriplegic cerebral palsy, C has compromised respiratory function, caused by a combination of his prematurity, kyphoscoliosis and unsafe swallowing reflex as well as chronic aspiration).

19. The NJ tube, which has to be inserted by a radiologist using x-rays to ensure it is positioned safely, was found to have been removed twice in November 2016; once on 17th November and again on 24th November 2016. Its removal both compromised his physical safety and the ability to provide C with sufficient nourishment. It is the local authority's case that the tube was deliberately removed by his mother. The re-insertion of the NJ tube necessitated this already very fragile and weak child to be exposed to repeated radiation further compromising his overall health.

20. On 8th December 2016 the case was before the Family Court and her Honour Judge Sapnara made an ICO. On 9th December 2016 C was transferred to ICU with a chest infection. MC refused consent for a PEG-J to be inserted, so that an application had to be made under the inherent jurisdiction for permission for a gastronomy procedure to be carried out. On 19th December 2016 by an order of Mr Justice Francis, which records the parties' agreement, it was ordered that C should undergo a gastrostomy for the insertion of a PEG-J (percutaneous endoscopic gastro-jejeunoscomy) tube.

21. The operation took place on 10th January 2017 after recovery C was discharged to the care of the local children's hospice on 20th January 2017, as a holding position, I have heard evidence about MC's behaviour on C's transfer to which I shall return. C was re-admitted to RH gastroenterology ward the next day. His condition deteriorated, and on 24th January 2017 he was admitted to ICU with sepsis, multi-organ failure, lower respiratory tract infection, likely secondary to respiratory rabdomyolysis and PEG site infection. By 27th January 2017 the view of the treating clinicians was that further invasive treatment was risky and that the burdens of such treatment, in C's case, would outweigh the benefits and that a ceiling of care should be established.

22. Pending the determination of the court of the intervening application by the Trust, C was intubated and placed on ventilation so that he could be transferred to St Mary's Hospital PICU for kidney dialysis (continuous renal replacement therapy, known as CRRT or haemofiltration). Since then his condition has improved; C has been

extubated and discharged from PICU in St Mary's. On the 8th February I was told by Dr V (Consultant Paediatric Intensivist at RH) that C has continued to recover and was expected to be well enough to be discharged and cared for in the community; however, by the time Dr K gave his oral evidence on 15th February C's condition had again deteriorated and there was concern he would have to be transferred to ICU again. His temperature had spiked to 40 degrees C (an indication of possible infection) and he was no longer in as stable a condition.

23. As a result of MC's opposition to the treatment that was being advised for C to provide him with sufficient nutrition and following a meeting between C's treating consultant Dr K with medical and other professionals MC was not allowed unsupervised time with C. A strategy meeting was held on 23rd January 2017.

24. From the notes I have seen and the evidence that I have heard it seems that there was no decision made to prohibit oral feeding until almost the middle of November.

The proceedings

25. The local authority applied for a care order on 25th November 2016. The child's father FC has not been located and has not been served with these proceedings. An interim care order (ICO) was made on 8th December 2016 by Her Honour Judge Sapnara; the ICO remains in place by the order of Mr Justice Moor dated 3rd February 2017. The case had been due to progress to a contested ICO/ fact-finding hearing in the Family Court on 1st February 2017 concerning one of the allegations in the local authority's threshold document in respect of the removal of the child's feeding tube by MC; but because of C' s deteriorated condition this was not appropriate nor possible for that hearing to go ahead. The hearing was abandoned because of C's deteriorating condition. I shall deal with the matter of the ICO in this judgment.

26. The NHS Trust (the Trust and 2nd Applicant) applied orally for declarations in respect of medical intervention and for a 'ceiling of care' to be put in place in respect of C. On 3rd February 2017 the case came before Mr Justice Moor in the applications list with a time estimate of half a day; the Trust was joined as an intervener to the care proceedings to make its application for declarations. This was a wholly inadequate time estimate as reading alone would take half a day and the court was unable to hear the application made on behalf of the trust; Moor J urged the parties to reach agreement.

27. This court has been told that no time estimate was ever given by the legal representatives of the Trust for a hearing of the application they were making; it is a requirement under the FPR 2010 r 1.3 that parties are required to help the court further the overriding objective; this includes assessing the time needed to hear a case, read the relevant documents and allow for the preparation of a judgement, including judgement writing. No explanation has been forthcoming as to why those representing the Trust so singularly failed to address this issue either prior to making their application, or after they had been before the court on 3rd February 2017.

28. Notwithstanding the fact that the court had not had sufficient time to hear the case, the Trust sought directions to have the matter listed on 8th February, again for half a day, when the case came before me. Once again the court time allocated was totally inadequate to deal with this case; not only was there insufficient time to read the

relevant papers no time was provided for judgment writing, to say nothing of hearing the evidence and submissions. The court heard the oral evidence of Dr V who had attended court to give evidence so that she did not need to return to give her evidence on another occasion as it was able to have the case listed for two days the following week on 15th and 16th February 2017 for further hearing. As MC was the only one of C's parents currently exercising parental responsibility in conjunction with the local authority a decision has to be taken as to where, and with whom, C should be placed should he be discharged from hospital into the community. The care proceedings cannot come to an end until later this year after this hearing.

Medical evidence

29. The Court has heard the evidence of Dr V and Dr K (two of C's treating physicians), and has seen and read reports from the hospital where C has been treated and together with the oral evidence of Dr D who had provided a second opinion, he is another paediatric intensivist from K Hospital. The guardian has been given permission to instruct Dr K-J (a paediatrician with a specialism in neuro-disability) to carry out a neurological assessment of C (as recommended by Dr D) and that evidence will not be available until 17th March 2017. The evidence is necessary to assess the extent of C's neurological disability and to provide advice as to the optimum treatment available for him.

30. Dr D is not a treating clinician and I accept that his opinion can be regarded as an independent second opinion. It is the unchallenged evidence of all the witnesses and from his medical records that C responds to pain by becoming distressed. The court has heard that C shows signs of contentment, and of enjoying appropriate stimulation such as by touch, or sound and that he likes coloured lights (evidence of J).

31. Dr D explained to the court in some detail that C's condition will deteriorate. He had an abdominal CT which has shown glass changes in his lungs caused by chronic micro-aspiration of his own secretions (see the discharge summary from M Hospital). Dr D described C as being in a *"vicious cycle"* of lung infections causing further lung damage which, in turn make further lung infections very likely, which cause further lung damage leading to further infection. It is his opinion that C is likely to have frequent re-admission to hospital in the short term; that is even presuming he is able to be discharged from hospital, in the first place. Dr V explained that C's is now on a *"downward trajectory"* which is common to people with cerebral palsy entering puberty; however, C is in the worst prognostic category for such patients as he has cerebral palsy with a gross motor functional score of 5 with gastrostomy feeding.

32. It is submitted by the Trust that the question for the court is whether it is in C's best interests to authorise the escalation of his care to give invasive treatment. On behalf of the Trust the case of *Aintree University Hospital's NHS Trust v James* was cited, quoting Baroness Hale (see below). The best interests test is an objective one. Baroness Hale gave guidance concerning the wishes of the patient at [45]; that those should be taken into account *"in so far as it is possible to ascertain them"*. In C's case it is not possible to ascertain his wishes and feelings directly, nor what his attitude would be to the invasive treatments. The court is put in a position where its evaluation of his social and psychological welfare has to be guided by an assessment of the medical benefits and burdens of the treatment (see below).

33. There is no conflict in the medical evidence of Dr D, Dr K and Dr V that invasive treatments cannot reverse or improve C's underlying conditions. While it does not mean that such treatment would not prolong his life in certain situations I have to consider whether it or they are likely to result in an improvement for C or whether it is likely to leave him more disabled than before. The example is of CPR and its limited prospects of success and the risk that, if revived, C would be even more seriously disabled than before; a real risk for C is that he will sustain further injury as a result of the treatment such as broken ribs, or infection which could even lead to fatality by acquiring a central line infection or ventilation induced pneumonia. The curvature of his spine compromises his ability to breathe as it restricts his lungs and limits his respiratory capacity; this condition has worsened and will continue to do so; it makes aspiration more likely and more serious and has reduced his ability to recover from any further insult or infection.

34. Moreover, invasive treatments, involving the placing of central venous lines in his neck or groin, require sedation, immobilisation and unconsciousness. The impulse to take whatever action possible to prolong C's life is entirely understandable, certainly from his mother's view point but it is more questionable when one considers the fact that doing so is more likely than not to further compromise his quality of life. The intensity of the process of applying invasive treatments would mean that for the period the treatment is required C would have little or no contact with his mother and carers. All of these treatments carry significant risk and offer no guarantee of the prolongation of C's life; indeed, they bring with them measurable costs. Every tube that is inserted is an invasion to his body and carries a risk of infection and/or further ventilator-associated lung injury. If the risks of invasive treatment are most likely to cause C increased suffering and produce no commensurate benefit it cannot be in his best interests; even given C's or any human being's desire to survive. C's life expectancy is short and nearing its end, those treating him (and Dr D) have explained to me carefully how they wish to provide him with the optimal care and comfort to make the remainder of his short life as pain-free and as comfortable as is possible.

The Law

35. There is no dispute between the parties as to the law; the decision that the court makes about withholding treatment is one that is founded on what is judged to be in C's best interests. The court is being asked by the Trust to make an order that allows for certain invasive treatment to be withheld in future. It is the responsibility of a parent or parents to make decisions on behalf of their child including any consenting to medical treatment or agreeing for some treatment, that would otherwise be available, to be withheld. When, as here, parents do not agree with the proposed treatment or withdrawal proposed by the clinicians responsible for their child's care, 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.

36. 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)".

37. The law is well established and so there is no need for extensive reference to authority and case law. A dispute has arisen between the hospital and the parent who shares parental responsibility with the local authority by virtue of the ICO. The local authority accepts the advice of the Trust's doctors as being in C's best interests and because of the dispute between the parent and the local authority the court will review the basis of the ICO before reaching a decision as to the withholding of treatment. C's guardian, having listened to the evidence, supports the application for declarations but asks that any declarations as to withholding care are interim declarations until Dr K-J's evidence is available; so that they may be reviewed if necessary.

38. In this situation where there is a dispute between those with parental responsibility, and a dispute between the Trust and a parent, the hospital Trust had to apply to the court to make a decision, this jurisdiction can only be exercised in this case because C as a child, lacks the capacity to make a decision for himself. This decision must be taken by applying an objective test in order to determine what is in the best interests of the patient, in this case C. When considering his best interests, I shall include his medical condition, along with his emotional and sensory perceptions, including his ability to give and receive love and affection, his pleasures, his enjoyment of his surroundings, and his pain and suffering. I keep in mind that he, too, will possess the human instinct to survive and prolong life, because the individual human instinct and desire to survive is strong and must be presumed to be so in C; as the patient subject to this application; a very strong presumption must be attached to the prolongation of life.

39. Notwithstanding the strength of that presumption (as expressed by Lord Donaldson of Lymington in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33) it is not absolute; *"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."*

40. The decision is to be wholly based on the specific facts of the individual case. The views and opinions of the treating clinicians and medical professionals and the parent, or others exercising parental responsibility, must be carefully taken into consideration. This mother has spent a great deal of time with C, more time than anybody else, and her view has considerable value because she knows C so well; but I keep in mind that the view of any parent is highly likely, and understandably, to be coloured by her own emotions, feelings and beliefs. It is clear from her own actions, for example that C's mother has held the belief for some years that C should be fed orally, despite the fact that he has suffered malnutrition as a result of the lack of the supplementary feeding that he so obviously needed; C is severely malnourished, his weight between 20 and 25 kilograms in a boy of 13 years old.

41. The wishes of any parent may serve to inform and provide explanatory background as to the quality of the child's life, including that relationship with his parent but it is subjective, and not necessarily evidence which is relevant to an objective view of the best interests of the child.

42. The court notes 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)."*

43. In the case of *Re A (A Child)* [2016] EWCA Civ 759 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."*

44. At [39] Lady Hale 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"*

Evidence regarding C's care/ Interim Care Order

45. The court heard from Y, a senior sister responsible for some of the nursing shifts caring for C while he was in hospital (but not in ICU), and from J, a care support worker employed on behalf of the local authority to provide practical support for C while he was in hospital. Finally, the court heard oral evidence from C's mother.

46. There is currently an interim care order in place. The local authority commenced care proceedings on 25th November 2016. The court has heard evidence of a care support worker, Dr K and Senior Staff Nurse Y in respect of MC's care of C in RH prior to care proceedings being issued in November. The court heard the oral evidence of MC both as to her behaviour and care of C in hospital in October and November 2016 and

her views regarding the declarations sought by the Trust. The court will make limited findings in respect of the continuation of the ICO as MC had opposed the court making an ICO previously. It is the local authority which brings the care proceedings and the burden of proof is on it. In making those findings the court will do so on the appropriate civil standard of proof, the balance of probabilities, as set out by the House of Lords in *Re B (Care Proceeding: Standard of Proof)* [2008] 2 FLR 141: keeping in mind the words of Lord Hoffman in *Re B* which apply any finding of fact: *"If a legal rule requires facts to be proved, a judge must decide whether or not it happened. There is no room for a finding that it might have happened. The law operates a binary system in which the only values are nought and one."*

47. The Court heard evidence from Dr K and Nurse Y that C is not capable of removing the NJ tube himself as he does not possess the physical ability to do so. This evidence was supported by the oral evidence of the care support worker J. She had clearly made considerable efforts to work along with MC and to build a positive relationship with her, and, she had spent many hours over several weeks supporting C and providing care for him, she had been with C five days a week from 21st October to the end of November 2016. Her observations of C and his mother were sympathetic, empathetic and humane. She demonstrated physically and orally what C could do, how he moved and what he sounded like. Of the witnesses the court heard, J's was the evidence that most brought C to life in the courtroom. J demonstrated how C much could move his hands, albeit in a very limited way, across and over the side of his face, and that he could not remove or even significantly move the NJ tube and the plasters.

48. All three witnesses gave evidence that MC refused to accept advice in respect of feeding C and was obstructive to those trying to carry out medical advice. Dr K gave evidence that on more than one occasion he had to threaten MC with being removed from the ward to get her to comply with the decision to stop feeding C orally; on one occasion security had to be called (and remain on the ward for an hour) to ensure that MC did attempt not feed C orally with food she had brought to the ward on a tray. To do so would have put him a grave risk of aspiration, so that his already compromised lungs would be at risk of further damage and he would require further painful suctioning; this was explained to MC repeatedly, by the doctors and other medical staff.

49. MC did not accept the medical opinion from the doctors and from the SALT specialists; she was insistent in her oral evidence that the hospital carry out a videofluroscopy in the face of advice from SALT that C's ability to swallow was so poor that he would at risk of aspiration from the dye used to perform a videofluroscopy. Dr K gave evidence about the length and placement of the NJ tube which is inserted down to the second part of the small bowel and the need for a radiologist to perform this procedure. It was his evidence, which the court accepts as self-evident, that although the tube may become dislodged by accident it would take the application of some force to pull out completely.

50. Clearly, C does not have the strength, physical co-ordination or ability to do so; nor is he able, as suggested by his mother to remove the plasters which kept the tube in place. Even though C's epilepsy means he is susceptible to seizure and dystonic spasm, Dr K explained that while, and at most, this could explain the tube being dislodged it would not lead to a complete extraction of the NJ tube. The court is well aware that each time the NJ tube was removed it had to be re-sited using x-rays which

exposed C to repeated doses of radiation as well as the discomfort of re-insertion for which he would have to be immobilised. When Dr. K had spoken to MC about it on 24th November 2016 she said the tube had "just fallen out". This incident was witnessed by J and a health care assistant (HCA). J described MC lifting C who was lying in his bed with the working end of the NJ tube passing between the bars of the panel on the side of the bed. When MC did so the tube became dislodged by several centimetres but most remained inside C's body. The HCA went to summon a doctor or nurse because this had happened leaving MC with J. J then described seeing MC holding the tube in her hand fully removed from C saying *"Oh! How did that happen!"* J said she did not see MC actually taking the tube out, but her evidence leads the court to the unavoidable conclusion that MC deliberately removed it, and was holding it in her hand. I have no doubt that this would have caused C some pain.

51. J gave further detailed evidence about MC's behaviour which she had observed when caring for C; this included MC's refusal to follow advice, her aggressive response on being challenged, her obduracy in continually lifting, dressing and re-dressing C when it was not necessary and feeding C being repeatedly told not to. J was not, as I have already said, unsympathetic to MC and was a witness who had tried to work with MC and to encourage her to heed the advice she was given, as well as offering her some personal support which she greatly needed. J described C enjoying the taste and texture for some foods in his mouth. She vividly described his way of communicating his pleasure by smiling, his pain (moaning and crying) and his dislike of persons and situations (when he would hiss – I was told he would sometimes hiss when doctors came near him). J was obviously much more attuned to C's reactions than the doctors or nursing staff who had not spent as much time with C.

52. I found MC's oral evidence in respect of the two removals of the NJ tube lacked any credibility; she said that it had happened, accidentally. She then claimed that C had removed the plasters holding the tube as they were no longer on C's face when the HCA returned. This is incredible C simply does not have the ability to pull plasters off using his fingers; he is not even able to hold a spoon to feed himself. She also claimed the tube fell out because the plasters were not properly attached to C and that it had occurred accidentally. Her evidence was contradictory and inconsistent; her assertions that C himself was somehow responsible for removing the tube from his gut is both disturbing and telling. As his mother she must be very aware of the limits of C's abilities, he is unable to make movements with his limbs voluntarily, that is quadriplegic spasticity. To suggest to me, in answer to a direct question, that he can use his fingers to pick at a plaster or grasp objects, something that is so patently obviously untrue, is an extraordinary example of hubris. In her determination to cover up for her own actions she has sought to "blame" her disabled son.

53. I find that MC pulled out the NJ tube on 24th November 2016. Given the history of the removal the NG tubes in the past and MC then resuming oral feeding regardless of the malnourishment C suffered as a result, along with the inherent unlikelihood, if not impossibility, of the NJ coming out accidentally, it is more likely than not that she was responsible for pulling the NJ tube out deliberately on the 17th November 2016. Not only was C's physical safety compromised in the act of removal, he was unable to receive the nutrition he needed and was subject to further discomfort and the weakening effects of radiation.

54. The evidence of Dr K, Senior Staff Sister Y and J about MC's argumentative, aggressive and challenging behaviour with the staff in RH and at the Hospice was consistent and credible, particularly after having seen MC give her evidence; during which she seldom answered the questions that were asked of her and was often belligerent and dissembling in her responses.

55. Dr K described having to ask her to leave the ward and go to another room because she was raising her voice and disturbing other patients and their parents. He told me that she had brought a tray of food to C's bedside and was intent on feeding him despite the fact that she knew C was not to be fed anything orally. He had to warn her that she would be removed from the ward if she persisted, which she did, security had to be called. Nurse Y gave similar evidence. I find that the evidence of Dr K and Y is credible and that MC behaved in the way they described, and that her behaviour put C at risk both directly and indirectly. These are incidents that occurred prior to care proceedings being issued and, by the removal of the NJ tubes alone, MC caused C to suffer significant harm.

56. When C was discharged to the Hospice on 20th December 2016, shortly after having the PEG-J fitted, he was accompanied by his mother and J. J described MC's behaviour; she was difficult to deal with and argumentative before, during and after the journey. When they got to the Hospice she lifted C onto her lap, despite having been told that to do so was contrary to his welfare. Once on her lap she proceeded to try to clothe him, she wanted to put a jumper on C. The jumper was in or on furniture behind where she was seated. The tube protruding from C's gut was attached to a feeding drip on a stand; MC leant back in her seat towards the jumper which was out of her reach, she was demanding that she be given the jumper, in doing so she was pulling the PEG-J tube until taut. MC was perfectly well aware of what she was doing because, according to J, MC said that she (J) was to get the jumper and to observe what she (J) had made MC do to the tube. This was reckless and aggressive behaviour, and I accept J's evidence, that this incident took place as she described. J was a careful witness who returned to her contemporaneous notes during her evidence to ensure that she was giving her best evidence. She had no reason at all to make up or falsify any account she gave, as was suggested by MC. Once again MC put C's safety and well-being at risk in a bid to ensure that she was in control of the situation, and of C himself.

57. The statutory provision for making an Interim Care Order under s 38 (2) CA 1989 is met as there are more than sufficient and reasonable grounds for believing that the circumstances with respect to the child are as set out in section 31(2).

Analysis of benefits and burdens: re *Wyatt v Portsmouth NHS Trust*

58. 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 outcome of ostensibly life-saving treatment and medical procedures in the case of C is something that it is necessary to consider along with all aspects of his welfare. Missing from the evidence before the court is a neurological assessment which will inform the treating physicians and thus the parties and the court as to the best treatment for C to alleviate his epilepsy and other symptoms. Any order or declaration made by the court regarding C's treatment will be an interim measure until the neurologist has reported. The court accepts the submission made on behalf of the Trust that *"The trust has sought to involve [C's]*

mother in its decision-making. The bond between them is clearly an important consideration. She is a constant presence in his life and sincerely believes that she has his best interests at heart. In determining the psychological and social aspects of the best interests test the court will of course carefully consider her views."

59. The Trust seeks a declaration that it would be lawful to withhold certain treatments, including the provision of inotropic drugs and vasopressor drugs which are used to support the heart rate, increase blood flow to support internal organs and potentially prolong life. These potential benefits are to be considered beside the burdens to C of such treatments; to provide them would necessitate the use of a central venous line (via the neck or groin) or by using intra-osseus route which requires forcing a needle into the bone (usually the tibia) or by drilling a hole in the bone: this extremely painful. The insertion of a central line would, in turn, require C to be put under sedation or anaesthesia; it will also raise the risk of infection of the line and of hospital acquired infection. These treatments will reduce further the already diminished blood platelets thereby increasing risk of bleeding, pain and discomfort.

60. The Trust contends that to provide continuous renal replacement therapy (CRRT) is not in C's best interests. The benefits of CRRT is that it would provide C with short-term replacement of his renal function which, if successful, would allow his kidneys to recover their natural function or, if unsuccessful, would enable kidney dialysis in the longer term. This treatment, which would potentially prolong C's life, has to be given in a specialist unit, and would probably require intubation for transfer from RH to the unit; as happened previously when C was transferred to M Hospital. Intubation requires large intravenous catheter to be inserted into a central vein of C's. The treatment is as, indicated, a short term measure only and if it does not work, C is unlikely to be a candidate for kidney dialysis because of his other conditions or co-morbidities.

61. The Trust also seeks a declaration that it is lawful to withhold CPR; including intubation and cardiac compressions. The benefit to C would be that if successful, it reverses the respiratory or cardiac arrest potentially prolonging C's life. The burden to C would be that CPR does not treat the cause of the cardiac or respiratory arrest and, if ineffective, often results in a reduction in the oxygen being supplied to the brain causing hypoxic brain damage; C's brain is already damaged. As already referred to, a burden of intubation is that it involves sedation and would immobilise C for a period potentially of days or weeks; which would be uncomfortable and reduce his ability to interact with anybody, including his mother and carers. More seriously, as far as C's health is concerned, intubation inevitably causes lung injury, which in turn, diminishes even further his already limited respiratory capacity, so substantially increasing the risk of lung infections such as ventilator associated pneumonia and ventilator associated lung injury. The former would be life-threatening for a child in C's condition; the latter will add to the "vicious cycle" described by Dr D.

62. There is an additional burden for C, as there is a possibility, if not a probability depending on his condition at the time, of not being able to extubate C which then requires a decision about whether or not to withdraw ventilation and insert a tracheostomy tube. Insertion of a tracheostomy tube would mean, of course, further invasive treatment bringing with it the risk of infection and associated burdens. It would also mean the loss of C's already limited, precious and restricted means of non-verbal communication. His carer, J, whose evidence I have referred to above,

explained C's manner of communication and how she, his mother and others familiar with and to C, were able to understand C communicating pleasure, pain, happiness, contentment, enjoyment, discomfort and displeasure; it would be a considerable burden to C to lose this inestimable connection with others, including his mother.

63. All treatments discussed here bring with them a burden for C in addition to the burdens set out above; when he is sedated or intubated it reduces his consciousness diminishing all his sensory perceptions, and so his ability to interact with or enjoy contact with his mother or his carers. J described to the court what it was like for C when it happened in December 2016 and in January 2017 after the PEG-J was inserted; C was not able to enjoy his surroundings or those around him as he had done previously. J also described how much comfort C derived from the presence of his mother.

64. J said that although MC tended to handle C in what J felt to be in a rough and brusque manner, C was always calmer and appeared soothed by her presence. MC undoubtedly brings to C comfort and reassurance, to reduce his ability to receive this solace is a very considerable burden to place on this very vulnerable child; it is clearly something that is of great significance in his life. The treatments which the Trust wants to withhold, have a limited potential to prolong C's life for an unknown period, but most probably transient period before his condition deteriorates once more. None of the treatments offer any prospect of recovery for C nor can they halt an inevitable deterioration leading to his death.

65. In this analysis I have kept in mind that C would wish to prolong his life for as long as he possibly could. His mother has said, unequivocally, that she wants any and all procedures and treatments with *any* potential for prolonging his life to be performed. I keep that in mind, but it is C's best interests that I must consider. In doing so it has to be recognised that C already suffers and experiences pain and discomfort and it is most likely that he already endures this regularly; in order to deal with secretions which would otherwise seriously compromise his respiratory function, C has to be routinely suctioned. The effect of suctioning clearly causes discomfort and likely pain for C displays it, not least by his limbs becoming stiff (dystonic) each time this procedure is carried out.

66. The benefits of the treatments which may prolong his life for a short time bring with them, as can be seen above, many burdens including the probability that they may hasten his death. All will cause him considerable pain and discomfort; they will all weaken this already vulnerable, fragile child and will all compromise his physical, psychological and emotional well-being, as well as reducing his ability to participate in and enjoy the society of others, including and especially, that of his mother. His frangible ability to communicate, at all, with MC and others will be removed. By allowing the medical treatment and the procedures associated with them, his decline towards his inevitable death will be all the more frightening, isolated and detached from the possibility of receiving, and in his limited way, giving, human warmth, love and comfort, directly as a result of the treatment he has received. It is clear to the court that C seeks and wants to be close to his mother (and to the carers that he likes) and would not want to end his life without being able to do so. It is in his best interests, taking all aspects of his life, medical, social, familial and emotional into account, that the Trust is granted the declarations that it seeks. They will be interim

declarations until they can be reviewed and refined in the light of a comprehensive neurological assessment.

67. The ICO pursuant to s38 of the CA 1989 will remain in force for the reasons I set out above.

68. This is my judgment.