

IMPORTANT NOTICE

This judgment may be published provided that in any report of the proceedings the child, her family members and the medical and nursing staff shall not be named in any report (unless named in the judgment). All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Case No: FD15P00387

Neutral Citation Number: [2015] EWHC 2920 (Fam)

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

19 October 2015

Before :

THE HONOURABLE MR JUSTICE PETER JACKSON

Sitting at Manchester Civil Justice Centre

Between :

Bolton NHS Foundation Trust

Applicant

-and-

C (by her Children's Guardian)

-and-

LB

-and-

PT

Respondents

Mungo Wenban-Smith (instructed by Hempsons Solicitors) for the Trust

Melanie Carew (instructed by Cafcass) for C

Hearing date: 15 October 2015

Judgment date: 19 October 2015

JUDGMENT

Re C (Baby: Withdrawal of Medical Treatment)

Mr Justice Peter Jackson:

Introduction

1. At the end of a hearing on 15 October, I made an order authorising the withdrawal of respiratory support from Chloe, who is eight months old. The form of order appears at the foot of this judgment. I now explain the circumstances and the reasons for the decision.
2. Chloe is her parents' only child. After an uncomplicated pregnancy, her mother went into labour at home on 28 January. Her parents set out to drive to hospital. It was an icy road and there was a hailstorm. Chloe was born in the car on the journey. When she arrived at hospital, she was in a critical condition with no spontaneous breathing or cardiac activity. She was resuscitated and her heart began to beat.
3. The next day, she was transferred to the neonatal intensive care unit operated by the Applicant Trust. Injury to her brain (hypoxic-ischaemic encephalopathy) was diagnosed as a result of the lack of oxygen at birth. She had no spontaneous movements, was hypotonic (floppy) and did not have a gag response.
4. Chloe has remained in intensive care all her life, receiving continuous medical support at the highest level. For some considerable time, the doctors treating her have been concerned that this treatment is not in her best interests. After many discussions with the parents, who wish for treatment to continue and for Chloe to be moved to another hospital, the Trust began these proceedings on 18 August. A Children's Guardian, Mr John Mellor, was appointed to represent Chloe.

The Trust's evidence

5. Chloe's medical condition is described in the evidence of Dr Paul Settle, consultant neonatologist and clinical lead.
6. She has had two MRI scans of her head, in February and April. The basal ganglia are affected with extensive loss of white matter. The neurological prognosis is poor.
7. Chloe has insufficient independent respiratory drive and throughout her life has required a high level of respiratory support. She has for the most part been on either a conventional ventilator or, as at present, on the higher level of support provided by High Frequency Oscillation Ventilation. Many efforts have been made to wean her to less intensive modalities that do not amount to

mechanical ventilation: Biphasic Positive Airway Pressure (BiPAP), Continuous Positive Airway Pressure (CPAP) and/or Optiflow. None of these efforts have succeeded for more than a few days before her breathing has deteriorated and she has been reintubated for ventilation. The intubation process, involving the passing of an endotracheal tube through her vocal cords into her trachea, is distressing for her, particularly if it is done in an emergency, when it may not be possible to administer the drugs that would make the process more tolerable.

8. Chloe cannot swallow or protect her own airway and therefore has to be fed by tube. Until March, she had a nasogastric tube, but she could not retain milk in her stomach and on occasions milk was aspirated into her lungs. A decision was made to feed her by continuous pump feed through a nasojejunal tube, which delivers food directly to the small intestine. When the tube becomes blocked or dislodged (as has happened at least five times) an operation has to be performed to replace it. Consideration has been given to alternative feeding methods (gastrostomy or fundoplication) but these would require major procedures to which Chloe's parents have not consented, and the coexisting issues in relation to breathing would remain.
9. In order to deliver her medications, and to feed her when her feeding tube is blocked, Chloe has a surgical intravenous line (a Peripherally Inserted Central Catheter, known as a Broviac line). She is nonetheless prone to infection and has needed antibiotic treatment about a dozen times.
10. Chloe's regular medications include domperidone and ranitidine in an attempt to control reflux, phenobarbitone in an attempt to prevent or reduce seizures, oramorph to reduce the distress caused by ventilation, baclofen to reduce muscle spasticity, artificial tears to prevent drying of the eyes caused by lack of blinking, and hyoscine patches to reduce oral secretions.
11. Chloe needs suctioning between 10 and 20 times a day to keep her airways clear. About once a week a laryngoscope has to be used for this procedure, but this does not always work and reintubation has to be performed.
12. Chloe's weight is within the 50th and 75th centiles. Her head circumference, in keeping with her severe brain injury, is below the .04th centile for her age. She receives regular physiotherapy to help clear secretions and reduce muscle stiffness. She is regularly turned to avoid pressure ulcers.
13. Apart from signs of distress, such as facial grimaces or extensor posturing during procedures, Chloe shows little sign of interacting with her environment. She does not open her eyes and makes little or no spontaneous movement. She is not responsive to visual stimulation and did not react to the insertion of the speculum during examination of her eyes. She has optic atrophy, suggesting that she may not have any sight. She does not respond to loud noises, suggesting that she may not have any hearing.

14. Dr Settle said that Chloe does not appear to be able to gain any pleasure from her environment. She only seems to respond to painful and distressing stimuli. This is in keeping with the nature of her brain injury, since experiencing pleasure requires a higher level of function than experiencing pain.
15. In the light of Chloe's severe and irreversible condition, the doctors have for some time been concerned that this intensive and continuous level of treatment may not be in her best interests. In the light of the parents' views, second opinions have been obtained from specialists who are independent of the Trust. A consultant neonatologist, Dr E, has advised that if Chloe survives she will suffer from profound developmental delay and cerebral palsy and that there is no additional treatment that could be offered elsewhere. A consultant neurologist, Dr T, has advised that Chloe has severe neurological damage and that long-term ventilation is not in her best interests.
16. The treating team has considered Chloe's circumstances in the light of the practice framework published by the Royal College of Paediatrics and Child Health this year: *Making decisions to limit treatment in life-limiting and life-threatening conditions in children*". This provides that treatment limitation can be considered because it is no longer in the child's best interests to continue where life is limited in quality:

"This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

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."

17. In the circumstances, the Trust's doctors seek the court's permission to progressively exubate Chloe and not reventilate her if, as expected, she deteriorates. If she should unexpectedly tolerate the removal of mechanical ventilation, she would continue to receive the lower levels of respiratory support. If she should not do so, palliative care will be provided to ensure that she is allowed to die with dignity and without further suffering.

18. If this plan is approved, the hospital will do everything possible to reach an accommodation with the parents about the arrangements. Visiting would be unrestricted and hospital accommodation would be offered so that the parents could be with Chloe at the end.

The position of the parents

19. Chloe's parents now visit her twice a week. The mother is reported as showing affection, talking to Chloe and stroking her, while the father is said to be more distant. The parents do not engage with the medical staff. The clinical team regularly attempts to contact the parents by telephone to keep them informed of progress. These calls are very rarely answered. The father has refused to provide the hospital with a postal address.
20. In a sad case of this kind, the Court always listens with the utmost care to the views of the child's parents. Very unfortunately, Chloe's parents have not participated in these proceedings. They have not meaningfully engaged with the representatives of the Trust or with the Guardian. They did not take part in the hearing, though I sent a message to them the day before, inviting them to attend, even if only by telephone.
21. As a result, my only knowledge of the parents' position comes from records of discussions between them and the doctors and from a few e-mails written by the father, who has throughout acted as spokesman for the parents, thereby making it difficult to gauge the independent feelings of the mother.
22. Having considered such information as I have from the parents, it unfortunately does not illuminate what is in Chloe's best interests. The father is exceptionally hostile to the treating team, expressing himself in the most vitriolic terms about the care she has been given, the doctors and nurses, the hospital, and the political system generally. In cases of this kind, the Court is familiar with disagreement or even mistrust between doctors and parents, but the level of antagonism expressed by this father towards those treating his daughter is beyond my experience.
23. Chloe is the subject of a child protection plan by her local authority, and it is therefore uncertain that she would be discharged into the care of her parents if she became fit to leave hospital.
24. The parents are of course free to express their beliefs. However, they risk depriving Chloe of options that exist where there is a working relationship. In particular, it would not be possible for Chloe to be discharged to a hospice without agreement and close cooperation between the parents, doctors and hospice.

The position of the Guardian

25. Mr Mellor is the most experienced of Children's Guardians. He visited Chloe on 23 September and spoke to the doctors and nurses. He describes Chloe in this way: *"Though intubated, surrounded by life support equipment and with various lines evident she looked lovely, in the way sleeping infants do. She appeared to me to be beautifully cared for."*
26. Giving evidence, Mr Mellor said that in his opinion the point has been reached where the burdens of treatment for Chloe far outweigh the benefits to her. The treatment causes her pain, discomfort and distress. The plan proposed by the Trust is the best way of allowing her to have as good a death as possible. He spoke to three of the nurses, all of whom have spent extensive periods looking after Chloe since she was one day old. He asked them what in their view made *"a good day"* for Chloe. Their reply was that it was a day without pain, a day on which she had not experienced significant discomfort or been subjected to distressing procedures.
27. Mr Mellor has made efforts to consult parents, offering to meet them wherever they choose. Their only response has been an email on the eve of the hearing in which, without changing their overall position, they appear to contemplate the possibility of palliative care. Mr Mellor said that it was wholly exceptional in his experience for parents to have refused to engage with him to this degree.

Principles

28. The starting point is a strong presumption that it is in a person's best interests to stay alive. But this is not an absolute, and there are cases where it will not be in the patient's interests to receive life-sustaining treatment. This has been stated in a series of decisions, starting with *In Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 and culminating in *Aintree University Hospitals NHS Foundation Trust v James* [2014] AC 591. These decisions are in harmony with Articles 2 and 3 of the European Convention on Human Rights, which provide that everyone's right to life shall be protected by law and that no one shall be subject to inhuman or degrading treatment. The Royal College's guidance, referred to above, is in conformity with this approach.
29. I incorporate by reference the ten propositions outlined by Holman J in *An NHS Trust v MB* [2006] EWHC 507 (Fam) at paragraph 16 and apply them in this case. I particularly affirm that the ultimate determination of the best interests is made by the Court, and not by the parents or the doctors, though their views are to be carefully considered. Further, although the views of doctors on medical issues will be a prominent feature in a case where a child is so medically dependent, the best interests evaluation considers all matters and not only medical ones. Lastly, I emphasise that in considering quality of life, the Court looks from the child's perspective and not from the perspective of others more fortunate.

Decision

30. I am in no doubt that this application should be granted. I accept the evidence of Dr Settle and of Mr Mellor. The benefits to Chloe of continued treatment consist only in the prolongation of her life by intensive medical intervention. The burdens, which only she has to bear, are considerable. She has no quality of life beyond remission from pain and distress. Even if she survives, she has no future to look forward to. She can experience none of the joys of life, but at best a continuous series of medical interventions.
31. The likely consequence of this decision is that Chloe will soon die. Given her sad experience of life, I hope that she will have a peaceful death. I hope that even now it will be possible to negotiate an agreement about her treatment that is acceptable to her parents, but this must not lead to her continuing to receive inappropriate treatment for any significant length of time. The positions of adults cannot prevail over the course that is in the best interests of this unfortunate little girl.
32. I end by expressing the Court's sympathy to Chloe's parents and its appreciation for the dedicated professionalism of her doctors and nurses in exceptionally difficult circumstances.
33. The relevant part of my order is in these terms:

AND UPON the applicant proposing a treatment plan for Chloe's respiratory support (the "Treatment Plan") as follows:

- 1) *The endotracheal tube by which Chloe currently receives ventilation support will be removed;*
- 2) *Respiratory support will be withdrawn by the stages set out below, moving to a lower level of support in the event that Chloe is assessed to be tolerating the existing level of support:*
 - a. *Biphasic Positive Airway Pressure (BiPAP);*
 - b. *Continuous Positive Airway Pressure (CPAP) and/or Optiflow;*
 - c. *Low flow oxygen.*
- 3) *If Chloe does not have the respiratory drive to tolerate a particular stage, a higher level of respiratory support will not be re-introduced;*
- 4) *In that event, Chloe shall instead be treated by way of palliative care, being given pain relief, sedation and nursing as may be appropriate to ensure that she suffers the least distress and pain.*

AND UPON Mr Mellor agreeing to write and if possible speak to Chloe's parents following this hearing to discuss its outcome and in particular to draw their

attention to the contents of paragraph 2 below, including the practical steps that would be required of them in order to put it into effect;

AND UPON the Court strongly encouraging the applicant and Chloe's parents to seek to reach an agreement in accordance with paragraph 2 below;

AND UPON the Court delivering a short judgment at the conclusion of the hearing and reserving its written decision;

IT IS ORDERED THAT:

- 1. It is lawful and in Chloe's best interests to withdraw all forms of respiratory support in accordance with the Treatment Plan set out above, even though she is likely to die as a result.*
- 2. If, and only if, it is agreed at any point between*
 - (i) the applicant, and*
 - (ii) Chloe's parents, and*
 - (iii) any identified hospice**that Chloe can be discharged to a hospice for palliative care, it shall be lawful and in her best interests for her to be discharged to such a hospice. The commencement of the Treatment Plan shall not be deferred beyond 14 days while all reasonable attempts are made to reach and implement such agreement.*
- 3. If agreement is not reached as contemplated by Paragraph 2 above, Chloe shall remain at the hospital with full access to her parents in accordance with the hospital's procedures.*
- 4. Any reporting of this case shall maintain the anonymity of Chloe, her family, and the clinical staff caring for her.*