Neutral Citation Number: [2015] EWHC 2778 (Fam)

Case No. FD15P00456

IN THE HIGH COURT OF JUSTICE

FAMILY DIVISION

IN THE MATTER OF THE INHERENT JURISDICTION OF THE HIGH COURT AND IN THE MATTER OF A CHILD X (AGED 11)

Royal Courts of Justice

Date 2nd October 2015

Before:

MR. JUSTICE BODEY

(**In Public**)

- -

BETWEEN:

AN NHS TRUST	Applicant
- and -	
W (Father) and W (Mother)	Respondents
- and -	
X (a Child, by his Children's Guardian)	2nd Respondent

- -

Miss Gollop appeared on behalf of the Applicant.

Miss Jacobs and Miss Stirling appeared on behalf of the Respondent father, Mr W.

The Respondent mother Mrs W was not present nor represented.

Mr. Chisholm appeared for X through his Children's Guardian.

- -

JUDGMENT

MR. JUSTICE BODEY:

[<u>*Judge's note:*</u> *In view of the extreme urgency (since the father wishes to go to the Court of Appeal) Counsel have over the weekend produced a note of my ex tempore Judgment, which I have now approved. I consider it is sufficient for its purpose and that to obtain an official transcript as well would run the risk of creating confusion. This version should therefore be treated as definitive and no other transcript need or should be bespoken.*]

1. This very sad case concerns a boy, a lad really, whom I will call "X", who has just turned 11 years of age. It is an application by an NHS Trust responsible for a paediatric hospital, which I will not identify, but which is a centre of excellence ("the First Hospital") for a Declaration that it would not be unlawful to withdraw medical support devices which are effectively keeping X alive. Without such devices in place in respect of his heart and lungs, X will die.

2. The application is strongly opposed by X's parents who are themselves devout Muslims. X is said to be as well. It is supported by CAFCASS as X's Children's Guardian. It, the application, was issued as recently as Monday of this week, the 28th September 2015 (today being Friday). On that day it was heard as a matter of great urgency by Holman J, who made various directions. After making special arrangements with the Clerk of the Rules, he managed to find today's date and the case has come before me for determination. Part of Holman J's order was that the case would be heard in open court, but with anonymisation. I have repeated that order today, but with the addition that the anonymity is to extend to the First Hospital.

3. The NHS Trust is today represented by Miss Gollop. The father is represented pro bono by Miss Jacobs and Miss Stirling. The Court is grateful to them both as, I am sure, is the father. Miss Jacobs has said everything that could have been said, and has put the father's case very well. At the beginning of the hearing today, she sought an adjournment which I refused. I shall come back to my reasons for doing so in due course. The mother has not been present in court, nor represented. She is herself unwell, does not live in London, and has two younger children to care for. She is aware that this hearing is taking place and has put in a statement which I have read. X's Children's Guardian is represented by Mr Chisholm.

4. I have read a number of statements and reports. I shall not identify the medical experts as it might lead to the identity of the First Hospital, but shall refer to them by the first seven initials of the alphabet. Dr A is a Consultant on the Cardiac Intensive Care Unit at the First Hospital. Dr B is a Consultant Paediatric Cardiologist at the First Hospital and Director of Cardiothoracic Care and Transplantation; he has a special interest in paediatric heart failure.

Dr C is a Cardiothoracic Surgeon. Dr D is a Consultant in Paediatrics Anaesthetics and Intensive Care at a second hospital ("the Second Hospital") who was asked by staff at the First Hospital for a second opinion. Dr E is a locum Consultant Intensivist at the Intensive Care Unit of the First Hospital. Dr F is Consultant on the Cardiac Intensive Unit at the First Hospital. Nurse G is the lead nurse for Extra Corporeal Membrane Oxygenation ("ECMO") and Ventricular Assist Devices at the First Hospital. Those are the various medical experts. I also have before me a statement by the father dated 1 October 2015, and a handwritten statement by the mother in person of the same date. The last statement which I have read is headed "Thoughts and Analysis" and is by the Children's Guardian, who visited X at the First Hospital yesterday. I have heard both Dr A and the father give oral evidence today.

5. As I have said, because of the urgency, this hearing has come on within four days of issue and there has not been the luxury of waiting for longer hearing time to be available. It has been a challenge to read the papers, hear evidence and submissions and consider them and prepare a judgment all within the confines of a one day case. Nevertheless, I give the judgment now because it is clearly necessary that I do so, although it will not be as well set out or succinct as might have been possible if I had reserved it over. That said (and although I have read and taken on board the technical and other details) I am not sure that this is a "detail" case. It seems to me to be one of those cases where a relatively broad overview suffices to reach a conclusion.

6. Before about June or July 2015 X was a normal, fit, healthy boy. Sadly, and catastrophically for him and his family, he was then struck down by a virus which attacked and compromised his heart and/or his heart functioning. He was taken to hospital (neither the First nor Second Hospital) very unwell and was admitted with end-stage heart failure. He was transferred on 30 July 2015 to the First Hospital. His heart was already then supported by ECMO – a short term procedure - and the plan of the First Hospital was to support his heart with longer term devices in order to enable him to be sustained and strengthened pending a heart transplant. There are apparently long waiting lists for paediatric heart donations to become available. It was thus always intended to be a "bridge to transplant".

7. The statements set out in considerable detail the numerous procedures which the team at the First Hospital have tried, given the numerous difficulties which nature has inflicted on X, most particularly excessive bleeding (the source of which has been difficult to predict or identify) and excessive blood clotting. Getting that essential balance right between bleeding and clotting has largely eluded even the greatly experienced professionals caring for X at the

First Hospital. I understand that on two occasions the bleeding problems have almost exhausted the blood supplies of the First Hospital.

8. The Skeleton Arguments of both Miss Gollop and Mr. Chisholm set out the various surgical and other procedures performed. For convenience, I refer to the summary of these procedures in Miss Gollop's Skeleton Argument as follows.

   Four days after X's admission to the First Hospital, an operation was performed on 3rd August 2015. Both the left and the right sides of X's heart needed devices and the pulmonary artery had to be occluded. The fitting of the heart devices mandated anti-coagulation to prevent clotting. On 13th August, a Berlin Heart was provided on the right side. This is a longer lasting device. At all times after the first operation, X suffered extraordinarily severe bleeding in his chest. Several chest explorations therefore followed, as did aggressive transfusion. The chest had to be left open (an infection risk) and closure prompted further massive haemorrhage. During the course of these explorations and other interventions, X's lungs became unable to provide sufficient oxygen. He was converted to ECMO; the Berlin Heart was removed and an Oxygenator was put into the right side. A number of adjustments were then performed to remove blood clots and to inflate the left lung. Notwithstanding these, the left lung was not inflating and so a stent was inserted on 7th September 2015. Since then, the right lung has deteriorated. X is reliant on the Oxygenator in the ECMO circuit for oxygen, whilst cardiac function is dependent on a "Heartware" device in the left heart. A CT scan on 10th September 2015 showed a large collection of blood in the left chest. This clot surrounds the left lung and occupies the space between the chest wall and heart. It is compressing the lung and airway and explains why attempts to inflate the left lung have been unsuccessful. Kidney function is deteriorating. Fluids are being restricted but, at the same time as suffering muscle wasting, X is swelling (although the extent of this is disputed) because his body cannot process fluids properly. I am satisfied from hearing Dr. A that X's kidney function has deteriorated.

9. Nutrition is via a naso-gastric tube into the small bowel. X's skin is breaking down. He gets blisters even from contact with bed sheets. This is a sign of him being nutritionally depleted and of being extremely poorly indeed. The maximum level of analgesia possible is being given, with Ketamine needed for any procedure such as turning. Even with Ketamine, contact provokes grimacing. The nursing team feel that it is cruel when they provide care.

10. There was a multi-disciplinary discussion at the First Hospital on 18th September 2015. All were agreed that there is no way safely to remove the clot. Even if there were, the lungs are

now too severely compromised to allow X to survive without an Oxygenator and mechanical circulatory support. As a result of this, X is no longer a candidate for heart transplant surgery and there is no prospect of him becoming such a candidate. Accordingly, the multi-disciplinary team was and is of the view that there is no surgical option and no prospect of one. X is in enormous pain which it is increasingly difficult to control. The nursing staff cannot change his sheets without him grimacing and crying. Given the circumstances of X's condition and the fact that there is no surgical option, the team's reluctant opinion is that treatment should now be withheld.

11. When these views were communicated to X's parents, they were not in agreement that life-sustaining treatment should be withheld. As a consequence, the First Hospital determined to obtain a second opinion. Accordingly the clinicians at the First Hospital asked a clinician at the Second Hospital, whom I have already identified as Dr D, to provide such a second opinion. Dr D travelled to the First Hospital on 17 September 2015. He spoke with the treating doctors and nurses, saw X and spoke with X's father twice. Dr D concluded that there was no hope of successfully performing a heart transplant because of the severe lung pathology. In answer to some questions from the father, he reiterated that there was no possibility of performing a heart transplant and it succeeding. He said, "*This is because the heart has to pump blood through normal lungs, otherwise it will fail.*" Dr D said he regarded a heart and lung transplant as a remote possibility but that this was not something he would advocate. There was a prospect of evacuation of the large blood clot by way of a left sided Thoracotomy, but this would have a less than 20% prospect of success. Again in answer to the father's questions, he said he was, "*clear that the chance of success of a surgical approach was less than 20% (and probably much less than that).*" He says that the team would not carry out such an operation at the Second Hospital (nor indeed would the clinicians at the First Hospital).

12. As I said, I heard Dr A give oral evidence, and he was cross examined by Miss Jacobs. There are several factual disputes between the father and the First Hospital, but these are not pivotal to my decisions. When time is of the essence, it would not be appropriate for the case to have to go off for further witnesses, e.g. nursing staff, to be called. That would not be proportionate in all the circumstances of the case.

13. The main strands of Dr A's oral evidence may be summarised thus. He reiterated that the multi-disciplinary team regard the heart and lung failure as being effectively irreversible. He described to me the large blood clot and explained how it is compressing X's left lung and compromising his ability to breathe; X's right lung cannot provide compensation for the left

lung's ineffective working. Dr A did not feel that the clot could be cleared without uncontrollable bleeding. If the mechanical devices were left *in situ*, he described the always present risk of their technical failure or breakdown, which he described as a "*big risk*". Other consequences of simply leaving the devices in place would or could be bleeding, which could occur anywhere, and if in the brain it would be catastrophic; also there would be progressive multi-organ failure, which could be renal or involve the liver or gut. He said that to go forward with the devices left in and working would lead to a slow death for X.

14. Dr A explained how X is unable to talk because of his breathing tube which passes through his vocal cords. As a result, communication is by nodding and minimal movements. X cannot move his fingers (F says he can point his fingers) and cannot grip a pen. X is sedated all of the time in order to reduce his anxiety and he is on a high level of pain killers. When asked about very recent blood results, Dr A described them as worse than the previous day and progressively worse over the last week. He said that X is producing poor quality urine, although the father told me that others at the First Hospital have described the urine as reasonably satisfactory. According to Dr. A there is blistering in certain areas which is breaking down eg in the groin area and left hip.

15. Cross examined by Mr Chisholm for the Guardian, Dr A told me that if there were to be a Thoracotomy performed then bleeding would be certain. He said he felt that such bleeding would or could be catastrophic, and the worst case scenario would be that X would bleed to death. He reiterated that if all the mechanical devices were left in place, then death would be inevitable and that "*we would just be prolonging it*". He reiterated that there is no prospect of treatment, and the medical team would not be able to keep X comfortable. He referred to there being a very considerable risk of infection from the various tubes, pipes and cannulae. In short Dr A agreed with one of the nurses that X is slowly dying. I asked Dr A if he could give me some opinion as to how long this might take if the mechanical devices were left in place. Dr A said, a number of weeks, with probable progressive renal and liver failure leading to death. I am told that if the devices are removed, death could occur as quickly as within minutes. The medical evidence is thus all one way, namely that the devices should be withdrawn. But I wish to touch on three other statements.

16. The first is Dr C's statement at page 27 of the bundle. As mentioned, Dr C is the Consultant Cardiothoracic Surgeon. He says that he has operated on X many times to remove blood clots, but that when he has done so there has been further bleeding and new clots have formed. Dr C says that X's lungs are "*so extensively damaged from his critical illness and clots around them, that a heart transplantation is no longer an option for him*." He gives an

approximate measurement of the clot presently in X's chest as "*filling approximately one third of his chest*". It was not his view that one could enter through the side of the Thorax by keyhole surgery using a Thorascope and camera to remove such a clot, but rather that the surgeon would need to go through front of X's chest, and manually evacuate the clot using his hands. Whichever way, Dr C says they would still encounter the same problem of re-bleeding. He says, "*We have seen profuse and unstoppable bleeding in X on many occasions due to the procedures we have had to carry out, and the bleeding comes through many locations rather than merely at the point of incision. If we did go ahead to evacuate the clot there would be a repeat of what has occurred before: massive uncontrolled bleeding that we would not be able to stop surgically or medically".* For that reason the surgeons at the First Hospital would not be prepared to carry out this procedure. "*Clinicians at [the First Hospital] have left no stone unturned in their attempts to treat this young boy and have nothing left to offer that can achieve a promising future. In my opinion we are lengthening X's suffering without any chance of success; this is as futile as it can get. There is no outcome that will lead to a successful outcome for X, as there is no potential for him to get a heart transplantation. His skin is breaking down, he has sores on his body and is incoherent. There is no possibility for him to reach the position where he is strong enough to have a heart transplant. There is no chance of success and, whilst there are risks of further treatment, there are no benefits*."

17. The second statement I wish to refer to specifically is that of Nurse G. She records what she describes as the opinion of all the nurses and clinical staff at the First Hospital that "*we have reached the limits of what is technically feasible… Prolonging X's life is not in his best interests… his organs are failing…*" She lists his nursing care requirements, namely that the tube in his nose requires frequent suctioning; that he needs two tubes for feeding and frequent suction, as he is unable to clear his oral secretions; and he needs eye care to maintain lubrication. She describes the areas of skin damage around where lines have entered through his outer tissues. She mentions muscle wastage and contracture of his joints, due to being in hospital for such a long time; and that he has an indwelling urinary catheter which is uncomfortable. She refers to the nursing team feeling that it is cruel that they should continue to deliver care when they can see that X is in pain. She describes the nursing staff as "*greatly experienced looking after seriously ill children*", as one would expect at the First Hospital.

18. The third statement I wish to mention is that of the CAFCASS Officer, following her visit to the First Hospital yesterday. She says that: "*X is a cherished young boy of 11 years, a keen footballer, with a passion for drama. He was due to start Secondary School this term. He presented as heavily sedated when I visited and showed no sign of distress, nor was there any*

positive communication as described in the papers. He was noticeably swollen, with numerous machines surrounding him… I was able to see a blister on his torso covered by a plaster." She goes on to describe the parents as educated and articulate parents who plainly love X. The mother is referred to as dignified and composed. The father is described as more emotional and as having thrown himself into the practicalities of the court proceedings. The Children's Guardian continues that "…*the parents appear to have a reasonable grasp of X's medical situation. They understand that he is no longer eligible for a heart transplant due to the difficulties with his lungs. However I am not confident that they are able to fully accept the very limited options now before the court. They appear to be of the view that if given time he could make some improvements, quite understandably they have latched on to him being described as 'stable'"*.

19. The Children's Guardian then records her own meeting with Dr A who explained to her that, that if the devices remained in place, then "…*X would still die, but it would be a prolonged decline waiting for something to go wrong. X would continue to swell, his skin would continue to blister and breakdown. He would become jaundiced and ultimately his passing would be unplanned. The hospital is of the view that this would be distressing for the family to witness, but ultimately also unpleasant and undignified for X*". Finally, stating her own conclusion on behalf of X, the Children's Guardian says "… *on balance I shared the hospitals view that allowing X to pass in a planned, managed way via withdrawal of treatment presents the optimal chance for him to pass with dignity and with the love and support of having his family around him*".

20. Turning to the parents' evidence, as I have said I have read both their statements. In his oral evidence the father told me how he and his wife, when she can come, pray together with X at his bedside. X nods that he can hear, and he is able to indicate if he is in pain by moving his shoulder, and can point to where he is in pain. X likes to see his younger brothers on Skype and is able to smile at them. The father helps with nursing care every day by massaging X and performing small exercises with X's arms and legs. The father saw the skin on X's back last night and thought it was perfect, if "*a wee bit swollen*." He did not feel that the skin condition was as bad as is being presented by the hospital. The father put particular weight on the fact (not explored in cross examination) that on two previous occasions when staff at the First Hospital had proposed the withdrawal of life support, X had in fact recovered. So the father believes that X has turned the corner twice before and can do so again. When asked in cross examination by Miss Gollop what exactly the father thought X would do again, the father replied that he thought X could resume his lung function, have a heart transplant and

then make a full recovery. The father agreed in cross examination that X's body was swollen last night, but in his view it was better this morning.

21. I said earlier that I would come back to the question of Miss Jacobs' application for an adjournment. She made the application at the outset on the basis that she and her junior had only recently received approximately 7,500 pages of X's medical records, and that despite their efforts they were still trying to master them. She was anxious to 'leave no stone unturned'. She asked me to adjourn the application until maybe next Tuesday, although no enquiries had been made as to whether the court could accommodate a hearing next week. The application was strongly resisted by the hospital Trust. Miss Gollop submitted that X cannot wait any longer and that a decision is called for. She maintained that his medical records would be highly unlikely to turn up anything of real significance, given the detailed statements of the hospital, adding that she herself has not perused the medical records, seeing no benefit in doing so. Lastly, she pointed out that the father had the advantage of representation on Monday by experienced counsel, Mr Bagchi QC, and that there was no obvious reason why such representation might not have continued. Mr Chisholm supported Miss Gollop's submissions in opposing any adjournment.

22. I did not agree to the application to adjourn because I found Miss Gollop's reasoning to be well founded. Of course conscientious counsel will want to feel that he or she has done everything possible to properly represent the interests of his or her client. However in these cases of urgency there is a question of proportionality to weigh in the balance. My judgment was and is that it was extremely unlikely that the medical records would contain anything that would significantly inform the decision which I have to take.

23. Regarding the relevant law, of course the welfare and interests of X are the Court's paramount consideration. I have also been referred to various authorities in this sphere with which I am well familiar. I refer particularly to Wyatt v Portsmouth NHS Trust [2006] 1 FLR 554 in which the court stated at [87]: "*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. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term 'best interests' encompasses medical, emotional, and all other welfare issues. The court must conduct a balancing exercise in which all the relevant factors are weighed and a helpful way of undertaking this exercise is to draw up a balance sheet.*" Pausing there, the nursing staff at the First Hospital have indeed drawn up a Balance Sheet of benefits and burdens.

24. The other authorities are to which I am referred are *An NHS Trust v MB* [2006] 2 FLR 319, *Aintree University Hospital v James* [2013] UKSC 67, and *Re SE (A Child)* [2015] 1 FLR 1316. Relevant extracts appear in the Skeleton Argument of Mr Chisholm. I do not propose to parrot them here but I have them well in mind.

25. Where does this resume of the evidence leave me? First I want to pay tribute to all of those involved in this very sad case, namely to the clinicians and nurses, who I am satisfied have used all their skill to do their best for X; also and especially to the parents who have had this catastrophic situation inflicted on them by the force of nature. This is every parent's nightmare and (as I said when I addressed the father personally before the case was opened) they have the fullest sympathy of the Court in their understandable pain and distress.

26. Nevertheless I have to examine the situation and the options and the balance of benefits and burdens as dispassionately as I can. I accept the expert evidence, and the oral evidence given by Dr A that there is no hope of any intervention which can now save X's life. I accept that sadly he is dying. I do not find that staff at the First Hospital have exaggerated X's condition. Where there are differences in the evidence as between them and the father, it may be that there are changes in X's external condition from time to time which give one observer a rather different impression from another. Or it may be that the father views the state of his much-loved son through the eyes of a father who fervently wishes to see improvements, when there are none, or none which are really significant. Sadly, I do not consider that the father's hopes for his son are realistic given the unanimous medical evidence which I have considered in detail. It seems clear to me that if death is inevitable, it would be better for X (and, so far as I can determine, what X would want) that his end should come in an orderly way with his family around him through the withdrawal of life support; rather than unpredictably as to time and manner and as part of a painful and slow decline, with his essential organs kept going only by artificial means. The evidence points all one way, as the Guardian observed. There are disadvantages of delay which are not counter-balanced by any realistic prospect of anything changing: or to repeat the above citation from Dr C's statement: "*There is no chance of success and, whilst there are risks of further treatment, there are no benefits*". Accordingly, and with a heavy heart, I consider that the NHS Trust has established its case. Notwithstanding the strong starting point of preserving life, I have to recognise that it is not always in the best interests of the child. I shall therefore grant the Declaration sought.

27. *Later:* I add the following reasons for and clarification of my decision in response to Miss Jacobs' application for permission to appeal. I have certainly weighed up all the benefits of

> the continued relation of the mechanical devices, when carrying out the balancing exercise as regards X's welfare and best interests. Those benefits appear particularly in the Balance Sheet prepared by the nursing team at the First Hospital referred to at paragraph 23 above, which I have read and taken into account in reaching my decision. There is, of course, a benefit to X in the pleasure which he gets from the society, support and closeness of his family; and from the knowledge and/or feeling which he must have of their love, care and support for him. It goes without saying that there is always 'a benefit' in being alive, as distinct from the finality of the alternative. These various benefits do not, however, outweigh the much stronger burdens and disadvantages already discussed.

On the 7th October 2015 the Court of Appeal dismissed an application by the parents for permission to appeal.