



Neutral Citation Number: [2019] EWHC 468 (Fam)

Case No: MAP1900343

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 27/02/2019

Before :

THE HONOURABLE MR JUSTICE HAYDEN

Between :

Manchester University Hospital NHS Foundation Trust	<u>Applicant</u>
- and -	
M	<u>1st Respondent</u>
(Acting by his Children’s Guardian)	
- and -	
OA	<u>2st Respondent</u>

Mr Burrows (instructed by Hill Dickinson LLP) for the **NHS Trust**
Ms Greenhalgh (instructed by Manchester City Council) for the **Local Authority**
Ms Mann (instructed by) for the **Guardian**
Ms White (instructed by Butcher and Barlow) for the **Father**

Hearing dates: 27 February 2019

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....
THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment)

in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. 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.

The Honourable Mr Justice Hayden :

1. I am concerned here with a little girl, M, who has just turned 13 months of age. She is presently the subject of an interim care order, along with her siblings. Concerns arose following a difficult situation in January 2019 when her parents were initially unable to agree to a gastrostomy being performed (as advised by her treating clinicians), although subsequently they did give their consent.
2. There is also a longstanding issue relating to mental health with both parents. On 18 February 2019 a further dispute arose, again in relation to M's treatment and, having heard evidence, I made an order authorising the removal of an infected peritoneal dialysis catheter. I made a declaration that insertion of a new one was in her best interests.
3. M was born with end stage renal failure. Prognosis in such circumstances, I have been told, is not propitious but far from forlorn. On 18 February 2019, I heard from two paediatric nephrologists who highlighted the background to the application, telling me that M, who weighed between 7 and 8kg would become eligible for a transplant if she were to achieve the weight of 10kg. All this is by way of the most sufficient superficial summary to the background of this application before me today.
4. During the process of inserting the new peritoneal dialysis catheter, pursuant to my decision, it became clear that the infection was rather more severe than had been anticipated.
5. I have heard today from Dr Dean Wallace, consultant paediatric nephrologist, responsible for M's care and I have had the benefit of an addendum to his earlier statement which sets out the change in M's medical status. I draw upon that to summarise the medical issues.
6. Pursuant to my order, M's dialysis catheter was removed, she having been accommodated on the emergency list on 19 February 2019. The reinsertion of a new catheter, as I have had explained to me, was delayed until 23 February 2018 the objective there had been to facilitate a more effective and complete treatment of the peritonitis from which she was suffering, by way of targeted antibiotics.
7. At the operation Dr Wallace noted a significant number of thick adhesions in the middle of the abdomen and pelvis. As he told me in his oral evidence, they were larger and more extensive than he had expected and the effect of this was to compromise the efficacy of the peritoneal dialysis catheter.
8. Dr Wallace has consulted with his paediatric and nephrology specialist colleagues throughout this case. It is a case which has, for entirely understandable reasons, caused him great concern and he has wanted properly to harness as much expertise as he can to provide the best treatment for his patient. In discussions with his surgical colleagues there was agreement that the adhesions were so widespread and extensive that it was not possible to identify a usable space for a new peritoneal catheter.
9. He says in his report that "*whilst we recognise that the current position of the catheter is sub-optimal, it was the only viable position it could be placed given the extensive scar tissue in the abdomen*". It is important that I read into this judgment the efforts made in the intervening period.

10. Peritoneal dialysis was recommenced on Sunday 24 February 2019 and whilst fluid was moving in and out of her abdomen it was clear that M was retaining fluid on each cycle, meaning that overall, fluid was being retained and not removed from her body. This is one of main indications for dialysis. It was recommenced on Monday 25 February 2019 but again, despite efforts with, this time, a higher concentration of dialysate, she continued to retain fluid on each cycle.
11. The process has not been wholly ineffective because it seems clear as I understand it that toxins have been expelled from the body and antibiotic treatment has addressed M's peritonitis effectively.
12. Finally, on 26 February 2019 the highest possible concentrate of dialysate was tried (3.86% dextrose) but fluid retention sadly continued.
13. In the last 48 hours, M has gained a net weight of 300 grams. This represents an entirely fluid gain. It has been during a period of intense fluid restriction and she has clinical signs as Dr Wallace has explained of accumulating fluid, otherwise known as an oedema. The risk from this is that she could develop respiratory difficulties and high blood pressure. This scenario, known as "ultrafiltration", arises in consequence of the very small surface area which is available for the dialysis, due to the extensive adhesions. It is complicated further by the location of the catheter position which was, in truth, all that was available. To this must be added the sequelae to the recent peritoneal infection.
14. The repositioning of the catheter has, therefore, been made impossible in light of the intra operative abdominal findings. In coming to this conclusion Dr Wallace conferred with his senior specialist colleague Dr Mohan Shenoy, who has been at court today and from whom I have heard.
15. The current situation is set out in Dr Wallace's addendum report which was written as recently as 1:30pm yesterday. That document is expressed, if I may say so, in clear and unambiguous terms and whilst it is sensitive to the parents it is nonetheless frank in its explanation of the limited options available.
16. The first and primary option is the performing of haemodialysis. That is not an uncomplicated procedure in any circumstances but is particularly fraught for M. It requires to be said that it would necessitate a procedure under general anaesthetic, probably by a surgeon or interventional radiologist, to site the haemodialysis catheter, in effect a central line, into an available large venous vessel in M's neck or groin. Through that line the blood can be cleaned and fluid effectively be removed with the assistance of the machine outside the body.
17. Mr Burrows, who appears on behalf of the NHS Trust, whose application this is, has described the process as complex. He highlights, of course, that even if successful it is viewed only as a bridge, in the hope that it is possible ultimately to achieve a renal transplant for M.
18. Whilst I said in my earlier judgment that M will be eligible for transplant when she reaches 10kg dry weight, the reality is that she will not be considered fit for transplant until either the end of this year or more likely the beginning of next year (by which point she will be 2 years of age). Even then and with a successful transplant, looking

into the future, from the most optimistic perspective, it remains the case that M's long-term care will continue to require vigilance with ongoing medical care.

19. Mr Burrows extracts from the medical reports the key risk factors attendant upon haemodialysis for M. There is M's longstanding history of hypotension. It is, I am told, difficult to maintain her blood pressure in a haemodialysis regime because at any given point a significant proportion of her blood is not inside her body. There is a risk of collapse. There is a risk of stroke. There is a risk of seizures. There is a risk of exposure to infection concomitant upon frequent blood transfusions. There is the ever-present risk of blockage. There is a real potential for catheter removal by accident or migration. There is a risk of catheter infection and thrombosis of the small blood vessels with large plastic catheters within.
20. Dr Wallace considers the ongoing risk of fatality in M's case is likely to be higher than for many receiving haemodialysis. However, as Dr Wallace emphasises in his statement, it is M's only real chance of survival.
21. The other option, as it has been termed, is not, in truth, a treatment option, it is a palliative care plan. It is expressed as "*conservative care with no further renal replacement therapy*" but in simple terms it involves permitting M to die comfortably and with dignity.
22. If haemodialysis is not pursued, the treating clinicians will cease the peritoneal dialysis and pursue symptomatic treatment with feeds and medication only. The objective would be to ensure M would be as comfortable as possible but recognising that she would die within a matter of weeks. This would be as a direct consequence of her renal failure.
23. When Dr Wallace wrote his report he, once again, consulted widely with his colleagues, as he has done throughout. Since writing his report he has consulted even more extensively, this time nationwide. He has enquired of other specialist units as to general experience with haemodialysis in infants under 10Kg and "*how they were getting on*". He told me with, if I may say so, admirable candour, that the approach within the profession was evenly balanced in favour of either the contemplated options in M's case. He surmised that an ethical committee would probably be split 50/50 as to which is the right course.
24. It is difficult to imagine a more onerous question for a court to address. However, since writing his report Dr Wallace has continued to think, reflect and to confer. When he came to give his evidence this morning, his conclusion, foreshadowed by counsel for the Trust in his opening submissions, was, he told me, by the narrowest of margins, that the haemodialysis option represented M's best interests. Having expressed himself in this way Dr Wallace logically and inevitably added that "*this is only for now*". By this he was signalling that the counter veiling factors were so delicately balanced that they could easily require to be revisited.
25. For Dr Wallace haemodialysis was indicated by three major factors:
 - 1) M's peritonitis was under control;

- 2) M has shown remarkable resilience already. A factor also identified by both her parents;
- 3) the obligation to preserve life runs deep within all human beings and within medical professionals in particular.
26. It is indeed a very delicate balance. It is only marginally tipped in the way Dr Wallace contends but I have, nonetheless, come to the clear conclusion that his assessment is correct. I believe that it would be premature to confine treatment to palliative options. The prospects of improving M's situation is real, not illusory. For completeness, I should say that the opinion is supported by M's guardian. Though it is evident from my analysis above, it requires to be identified that I have structured my approach within the framework of the relevant case law which must be identified.
27. The law is now relatively easy to state though, as I have previously observed, always difficult to apply in applications as sensitive and fact specific as this. I do not consider, in this ex-tempore judgment that an exegesis of the applicable law is required here, indeed the risk is that to do so might eclipse the lode star which guides the Court's approach i.e. *"the best interests of the child"*.
28. The test is encapsulated by Baroness Hale in **Aintree University Hospital NHS Trust v James [2013] UKSC 67**, namely:
- "[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it." ...*
- "[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be."*
29. In **Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust [2017] EWCA Civ 410**, McFarlane LJ observed:
- "As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view."*

30. MacDonald J reviewed the authorities and distilled the principles to be applied very recently in Kings College Hospital Foundation Trust v Haastrup [2018] EWHC 127 (Fam). Though extremely helpful, it is unnecessary for me to reprise that exercise here.
31. The Royal College of Paediatrics and Child Health has produced guidance, published March 2015: **Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: A Framework for Practice'**. The following is relevant:

“The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit: II When life is limited in quality This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise: 3 .Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life.....In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation.”

32. Having come to this conclusion, three issues arise. They may surface quickly and thus require to be addressed now. They are identified in Dr Wallace's report and reconfigured a little by Mr Burrows in his written document.
33. Firstly, **what would happen if the catheter ceased to function? Before a further attempt is made, would the case have to come back before the court?** Whilst I am clear that such a delicate balance can easily be tipped one way or another on a day to day basis, I consider that the approach of Dr Wallace, which Dr Shenoy tells me is a departmental approach, is cautious, collaborative and unwaveringly focused on M's needs. This is the route map.
34. Accordingly, in the event of catheter “non-function”, I do not consider it is necessary to return the matter to court to seek permission. This seems to me also to resonate with the very recent guide of the British Medical Association and the Royal College of Physicians in relation to CANH and adults who lack capacity to consent, the principles of which apply here by parity of analysis. In stating this I do not close the door to an application being made if the parties think it necessary.

35. The second issue: **If M became unacceptably symptomatic, i.e. if it was obvious that she was in pain and suffering on dialysis, then it is queried whether the hospital could decide themselves as to cessation of treatment or whether they would need to return to court.** The external indicators as to whether M maybe suffering will not necessarily be easy to identify or interpret but they would be evidenced, I have been told by collapse, repeat seizures and by cardiovascular instability. If such a situation arises I am clear that, in the circumstances of this case, the matter should be returned to court.
36. The third situation, which is a subtle but significant refinement of the second, is **what should happen in the event that haemodialysis is unsuccessful.** In such circumstances, because as has been made clear, it is the only option available, there would need to be an expedited plan of palliative care with a DNAR certificate. Again, this would require a return to court.
37. M's mum and dad oppose this course. They have a deep, profound and simple faith. They believe entirely in the power of prayer. They believe that M is a gift from God and I have no doubt that that is why they gave her the name they did. I note and respect their beliefs.
38. Both parents sadly suffer from mental health issues which may preclude their capacity fully to understand the choices that arise here. However, I am satisfied that their primary objection is predicated on the strength and vibrancy of their faith. The mother told me *"This is not only a medical problem, it is also a spiritual problem"*.
39. It is crucial that I record in this judgment that M's mother paid tribute to the medical staff whose professionalism she does not doubt and whose motivation to do their best for M she plainly thought was beyond any question. I agree with her.
40. Whilst I have deep respect for the parent's views and beliefs, I am charged, under the inherent jurisdictional powers of the High Court, with identifying where M's best interests lie. I am clear, for all the reasons I have set out, that this little girl, as Dr Wallace has said, has shown that she wants to fight. We do not know what the reality of the prospects will be and she faces many difficulties, but her situation is far from futile. In the weeks ahead I should like to signal, unequivocally, that it is the needs of this little girl that should drive the decision making and not the exigencies of this litigation. By that I mean if the situation changes the case should be returned quickly to court with the overall objective of preventing M's suffering.
41. By way of postscript, I would add that I have been enormously impressed by the commitment of the doctors and the hospital to this little girl who, I am entirely reassured, is receiving treatment of the highest quality, preserving her medical wellbeing but also her dignity, as the 13-month-old human being that she is.