Neutral Citation Number: [2019] EWCOP 29

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 08/05/2019

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

- -

Between :

Imperial College Healthcare An NHS Trust	**Applicant**
- and -	
MB	**1ST Respondent**
(by his litigation friend, the Official Solicitor)	
- and -	**2nd Respondent**
Others	

- -
- -

Ms Susanna Rickard (instructed by **Imperial College Healthcare An NHS Trust**) for the **NHS Trust**
Mr Bagchi QC, Ms Nicola Mackintosh QC (Hon) (instructed by Mackintosh Law the Official Solicitor) for **MB**
Ms Zoe Gannon (instructed by Local Authority) for the **Local Authority**

Hearing dates: 8th May 2019

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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.

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THE HONOURABLE MR JUSTICE HAYDEN

Mr Justice Hayden :

1. This is an application brought by the Imperial College Healthcare the NHS Trust in relation to MB who, having been born on 28 September 1994, is 24 years of age.

2. MB suffers from what is termed 'dyskonetic tetraplegic cerebral palsy', arising in consequence of birth injuries for which he received extensive damages, following a personal injury claim concluded in 2007.

3. It is perhaps significant that his mother takes issue with the terminology of his condition. She prefers to use the term 'dystonia'. This makes absolutely no difference at all to MB or anybody else but it is a signal of the level of conflict which has existed throughout these proceedings. MB's mother will not even agree with the doctors, even on the name of her son's condition.

4. There have been proceedings in the Court of Protection, resulting in litigation every year now since 2013. There is no doubt MB is aware of the litigation and that its impact upon him has not been positive. It is not really the litigation, that is the problem. It is the level of conflict within the family which runs very deep and I suspect is probably intractable.

5. MB and his family are of Lebanese origin. His parents are divorced and I was reminded, during the course of exchanges this morning, that he has three brothers, who have little prominence within the papers but who in different circumstances might have been central to MB's world.

6. For much of the brothers' childhood they were accommodated in local authority foster care homes. This occurred because the mother considered it to be her responsibility to put MB's interests before her other children. In order to focus on MB she considered it necessary for them to be placed in the care system. I am not going to comment on this, I do not know what distress she must have been in at the time. I record it as a fact simply because it signals, as clearly as anything could, her absolute devotion to MB. This has never abated. She has repeatedly and quite recently expressed the view that she would find life unbearable without MB. He, she says, is *'her oxygen'*. By this she again signals how much she needs her son. That he needs her is self-evident. I note that in her detailed and careful judgment in July 2017 Her Honour Judge Hilder, concluded, upon the basis of expert opinion, MB and his mother were emotionally enmeshed. I am entirely clear that this remains the position.

7. Until his admission to St Mary's hospital, on 3rd December 2018, MB lived with his mother at a home purchased on his behalf in London, within the London Borough of Brent. The maternal grandmother also lived there. It is clear that MB is a delightful and engaging young man who until his relatively recent decline, was able to display a mischievous sense of humour, a real ability to relate to people, notwithstanding his communication difficulties, and a diffident willingness to be teased, gently, by those who had come to know him well.

8. The admission to St Mary's came about in consequence of a sepsis. Although as a child MB was able to attend school and to walk with the support of a frame, his decline has been progressive with worsening difficulties relating to swallowing, nutrition, and advancing weakness. It is a long time now since he was able to walk.

The sepsis necessitating admission in December 2018 was originally thought to relate to a urine infection, or PEG site infection, but he suddenly suffered a sudden drop in haemoglobin levels early in his admission which may have been consequent on gastro-intestinal bleeding, but it caused a cardiac compromise that was very close to cardiac arrest. His general condition was such that he thereafter developed severe pneumonia to his left lung and he has remained either in the intensive care unit or the acute respiratory unit since. At present, he is on the intensive care unit.

9. MB is very severely malnourished. Since his admission he has lost 12.8kg, which is a 34% weight change in a five-month period. His current weight is approximately 25kg, or around 4 stones. Self-evidently, he is properly described as emaciated. He has a very fragile skin tissue, which renders him vulnerable to infection, which in his situation could quickly become life-threatening. He also has severe loss of muscle, and as a consequence of his malnutrition he is vulnerable to further skin breakdown. In a detailed and helpful report prepared for this application, Dr Chris Lambert, a consultant in intensive care at St Mary's Hospital, has noted that there are two suspected deep tissue pressure ulcers to MB's sacrum. This has caused there to be a change to his sleeping arrangements. Dr Lambert told me in evidence that a new, pressure relieving mattress was brought in to provide better support on the specific recommendation of the tissue viability team. It is interesting and disturbing that MB's mother disagreed with this provision, having taken an alternative view as to what is in her son's interests.

10. The history of this case is a litany of disagreement and conflict. Not only does it provide an environment which is not conducive to meeting MB's emotional needs, but it provides an arena in which professional confusion becomes more likely, as well as hesitation and procrastination about treatment.

11. MB has very poor gut mobility. This is a facet of his condition. It has been lifelong, but as his recent decline in weight testifies, it has progressed. The poor gut mobility and consequent slow gastric evacuation has led to recurrent episodes of gastric reflux and aspiration of feed into the lungs. I pause to say that may have been associated with the sepsis leading to the admission, in December. His swallow is unsafe, and he has in order to address that, been provided with a percutaneous gastrostomy tube (PEG tube), to allow feeding directly into his stomach. Feeding directly to the duodenum was unsuccessful. So, he is currently on parenteral nutrition, which despite the efforts of his clinicians, has not been able to reverse his physical decline.

12. The lung problems he has had have caused him to experience what Dr Lambert described to me in evidence as *'recurrent mucus plugging and lung collapse.'* This has led to cycles of intubation and extubation, to remove secretions, to re-expand his lungs and allow ventilator support. It is manifest that those have been distressing to MB. His present arrangements i.e. intubation with an orotracheal tube have been described as distressing to him, both by his solicitor Ms Mackintosh QC (Hon), and Dr Lambert. He is unable to clear his lungs without direct suctioning through his tube, and has repeatedly deteriorated due to respiratory problems. He is just plainly very uncomfortable with this.

13. What is concerning is that this was identified, to my mind, beyond any real contrary argument now as long ago as 12th April, by Dr Gomez. Dr Lambert told me that the reason that the procedure had not already been undertaken was that the hospital staff

had spent the intervening three and a half weeks trying to liaise and to use his phrase, *'mediate'* with the family.

14. Mediation is usually a concept applicable to two conflicting parties. But there were not two conflicting parties here. There were hospital staff, treating clinicians, and a patient. The parents and family have their views, but they must never be allowed to drown out the views of P. In this case, on this occasion, they did.

15. I have reminded the NHS Trust to be vigilant to see that this does not become a pattern. The delay in bringing this application has been inimical to MB's welfare. This is not merely my analysis, having heard the evidence and read the papers, it is the opinion of Dr Lambert, and the view of the Official Solicitor acting on MB's behalf.

16. I do not doubt for a single moment that the parents and family have intended well. But there is a chasm between their intentions and the reality of the consequences. In this parlous state, this brave 24-year-old young man has been subject to pain and discomfort which could and ought to have been avoided.

17. The lung problem is due to an absent cough, an absent gag, the diminishment of the respiratory muscles as a consequence of the malnutrition, a high secretion load, a recurrent gastro-oesophageal reflux due to the gut problems I have alluded to, a fragility in the upper airways tissues, and a significant decline in MB's general posture such that his head is now almost permanently tilted upwards at a right angle. As Dr Lambert commented this is consequent upon the hyper-extension of the rear neck muscles.

18. Added to this is the progressive curvature of the spine, which affects his ability to breathe and to cough up his secretions. The consensus, from which there is no departure, is that MB's needs in terms of his lung function and respiration can only properly be met by the insertion of the tracheostomy. There are clinical advantages to this in terms of his general ability to address the removal of secretions from the lung. It is thought that the tracheostomy will not be in itself essential for his breathing, and thus the immediate consequence more or less to MB is that he will achieve what Dr Lambert described to me as 'liberation' from the mechanical ventilator. I think that term is carefully chosen, and accurate, for it permits, at least theoretically, the possibility that MB might return home. Certainly, it would secure his liberation from the intensive care unit.

19. Ms Mackintosh went to visit MB yesterday. The challenges for him in communication are such that he can now only effectively communicate by what has been referred to as a 'communications book.' This is, I am told, around a 150 - 200 page lever arch file with laminated pages which is intended to cover the whole gamut of MB's communication options.

20. It is an illustration of how much professional effort has been put into his welfare, but equally, the parameters of his ability to communicate his wishes and feelings. When determining, as I am required to do in this application, where his best interests lie, I am required to have regard to M's wishes and feelings. I emphasise that I regard the two as distinct and separate.

21. Dr Lambert, who impressed me as a kind, skilled and conscientious doctor, told me that in reality he was not able to communicate with his patient at all. He relied on others to do that. That is clearly a significant impediment to the doctor -patient relationship.

22. One of the few benefits of this corrosive and protracted litigation is that MB has had the benefit of an extremely experienced solicitor. Today, she gave evidence in order that I could get to know something of MB's character and personality. It is plain to all that the years in which she has been representing her client have enabled her to communicate very effectively with him. She tells me that one of the effects of the orotracheal tube presently in place is that it actively inhibits MB's already very limited capacity to communicate, in itself a very powerful indicator of its continued unsuitability. The tube is rigid. It simply doesn't allow him to move his head, or his eyes, which is the primary way by which he communicates. MB's head is almost permanently, as described to me, to one side.

23. Notwithstanding all this however, MB was able to communicate that he understood the explanation of the tracheostomy. Ms Mackintosh was entirely convinced, and I accept, that he listened carefully to her as she explained its purpose. He also indicated that he believed the doctors, and trusted them. Those I infer from her evidence are incorporated within the range of responses in the communication handbook.

24. MB was told about a second procedure which has been contemplated, and which if not actively opposed by the mother, is certainly extensively queried. This is the proposal to provide an injection of Botox to the neck, the objective of which is to ease the muscles and to enable his head to return to an almost entirely normal position.

25. There is much optimism that it might work. There are very few negatives to it, particularly having regard to MB's general situation as a whole, but the potential benefits, if successful, are striking. It is difficult to see how anybody could objectively recoil from such an opportunity. I am not entirely clear whether MB fully understood what was involved in that secondary procedure but I do accept from Ms Mackintosh that he showed no opposition. I can't help but notice that it is perhaps not dissimilar to the position of his mother. In any event, I am entirely clear that he was able to communicate the response he intended to, and it was received by Ms Mackintosh.

26. Finally, MB's voice did come to be heard on this, in the clearest and most human of terms. He told Ms Mackintosh that he wanted to eat. He said he wanted to eat meat. This also revealed, in my assessment, his continuing fortitude in the face of his condition, as he believes that will enable him to get stronger and better.

27. That seems unlikely, having regard to the broad canvas of the evidence, but it reveals this young man's spirit.

28. MB is a young man who has, I am told, revealed, himself to have in the past, had *'an eye for the young women'*, I had better be careful what I say of this, but, I am told, that he exhibited a preference for blonde women, one of whom worked at the pharmacy and another of whom worked at the milkshake stall. I record this because it shows this young man's determined engagement with the world.

29. It seems to me that the determination to look out to the world and to fight for what remains of his life is also expressed in his desire to clean his teeth. The simple feeling of having clean teeth, and for his mouth to be cleaned, perhaps reflecting something of his continuing self-esteem. He also was clear that he wanted to see his Uncle Sam in particular and, his Aunty Amy. He appeared apprehensive about how his parents might react to this, for this extended family have been chest high in conflict for so long.

30. It struck me that it was by a narrow margin that Senior Judge Hilder concluded that MB's place should remain with his mother. We are in early May, and he has been in hospital since December. I have no doubt his mother has visited regularly, but I think it may be tentatively encouraging that he has been prepared to put his head above the parapet of conflict and indicate he wishes to see his Uncle Sam. I am profoundly determined that he should do so and after the discussion with Mr Bagchi QC, I have decided to make a declaration to that effect.

31. MB made it absolutely plain that he was uncomfortable. He wanted to be turned. On his present ventilation regime, he requires three staff and has to wait for their availability in a busy hospital.

32. The wider family leave decisions of medical treatment to this highly experienced medical team. The father now, somewhat belatedly it seems to me, agrees with the need for a tracheostomy. I am simply not clear what the mother's position is but I do note that despite the continuing course of her objections and the delay that has ensued, she has chosen not to attend court to articulate those views today.

33. I am sure, and no-one could doubt, that she loves her son deeply, but the expression of her love has, despite her genuine motivation, found its consequence to be repeatedly inimical to her son's welfare.

34. MB has needs which are plainly complex in every aspect of his daily life. He has had in recent years, and I am not entirely sure of the timescales, a succession of case managers. The desirability of continuity in his care is obvious. Not only in relation to the practicalities of the medical treatment, but because he is entitled to be afforded the best possible opportunity to communicate. I have the strong sense that even now, and at this stage, he has greater potential to communicate than is realised. This can be improved if there is continuity of case management at a senior level. It is also a fact that he did not have a lead clinician. Sometimes the courtroom can be an informative venue for treating clinicians, just as listening to treating clinicians is informative to the Court. I think Dr Lambert realised that there needed to be a clear framework of clinical continuity, just as there requires to be continuity in every aspect of MB's welfare. Ms Rickard of counsel had a conference with her team over the luncheon adjournment and she told me that Dr Lambert, having thought about it, considered and I emphasise that the idea was generated from him, that he should act as the overall lead clinician, by which was meant he would consult with the clinicians on duty so that information was shared seamlessly from day to day and week to week. He would be the single point, and this I emphasise, for discussion with the family. He would feed back to them the information that came to him from the consultant on duty. Moreover, he emphasised, because he struck me as entirely sensitive to the needs of the family, that a single point of contact would likely make things easier for

the family when one person is communicating to them regularly on the development of treatment.

35. I have, I hope, made it clear that there are compelling reasons why the tracheostomy is essential in promoting MB's comfort and welfare. I have emphasised too the potential for the Botox process to reduce the painful hyperextension of the neck to open up the upper airways and to improve the facility to cough and swallow.

36. MB is still only 24. The intensive adult care unit is, as Dr Lambert points out, a very frightening place to live your life, not least because of the traumatic realities of life for the others on the unit. The tracheostomy is likely to secure as Dr Lambert puts it, *'MB's liberation from that unit'*. So, in addition to the manifest medical benefits, there must be surely a huge boost to the quality of his life in general by such a process.

37. Finally, because it would be wrong to avoid it, I note that it is the clinical opinion that the prognosis for MB is poor. The underlying problems are progressive. There is little that I have identified in his present condition that is reversible, as Dr Lambert says, probably not even his weight loss.

38. Based on the trajectory of the past five months intensive inpatient admission, the view of the clinical team is that life for MB is limited and whilst it is impossible to be in any way precise, the view is that it would be surprising if he lived longer than another 12 months. Any plan for his welfare has not merely to absorb this, but to place it at the centre of the process, because in the context of this life expectancy, the planning is, in truth, palliative. That has a direct impact upon what will be appropriate for him.

39. Thus, as Dr Lambert says, the priority now must be for MB's comfort, to facilitate his communication, to see that he has as much liberty as possible, and that he has the opportunity to taste food if that is possible, and the opportunity to interact with those with whom he wishes to. Time may be short. It is for all these reasons, emphasising particularly MB's own views, that I am able to make the declarations that it is in his interests for him to receive:

    i) The insertion of tracheostomy and associated treatment at the direction of the treating team, including the administration of a brief general anaesthetic for purposes of this procedures;

    ii) botulinum toxin injections to the extensor muscles of his neck.

40. I also make the declaration that it is in MB's best interests to have contact with his Uncle Sam and Aunty Amy and such contact should be introduced as quickly as possible, prioritising the privacy of that relationship with his aunt and uncle, the terms of contact being at least for now, entirely a matter for the Trust.

41. If it is necessary for there to be another application, before it is heard, I will come and visit him myself, subject to everyone thinking that is appropriate.