



Neutral Citation Number: [2019] EWCOP 30

Case No: COP11327881

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 12/07/2019

Before :

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

Between :

Imperial College Healthcare An NHS Trust	<u>Applicant</u>
- and -	
MB	<u>1st Respondent</u>
(By his litigation friend, the Official Solicitor)	
- and -	
Others	<u>2nd Respondent</u>

Ms Susanna Rickard (instructed by **Imperial College Healthcare An NHS Trust**) for the **NHS Trust**

Mr Parishil Patel QC, Ms Nicola MacKintosh QC (instructed by Mackintosh Law the **Official Solicitor**) for **MB**

Ms Zoe Gannon (instructed by Local Authority) for the **Local Authority**

Hearing dates: 12th July 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.

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THE HONOURABLE MR JUSTICE HAYDEN

Mr Justice Hayden :

1. I am concerned here once again with the welfare of MB. In the course of this ex-tempore judgment I am referring to him by name but the transcript will be amended to ensure his privacy. I delivered an earlier judgment on 8th May 2019.
2. MB is of Lebanese origin. His, family, his brothers, his father, his uncle, his aunt, are all hugely important to him. But the focus of his life is his mother. Their relationship is intensely close, to the extent that that has not always been healthy for either of them. MB suffered a birth injury in consequence of medical negligence, which left him with a condition which is described as dyskinetic tetraplegic cerebral palsy. His physical disabilities are extensive.
3. In July of 2017, Senior Judge Hilder heard applications relating to MB's capacity to take medical decisions for himself. Though Judge Hilder recognised the nature and extent of the physical disabilities she described his mental functioning as having been "relatively spared".
4. During the course of the proceedings, I was asked if I would visit MB in hospital. Having listened to what had been said about him, and having read a great deal, I nonetheless found myself, at our meeting, rather surprised that MB was quite as physically fragile as he is. I suspect this is because the force of his personality resonates so clearly throughout the papers. His deterioration over the course of the last six months had been significant, and the papers had not signalled to me prior to our meeting the reality of the extent of it. He is tiny. His bones are thin. His wrists almost bone. But just as I was surprised by the extent of his physical deterioration, I was overwhelmed by the extent of his intellectual robustness, and the real force of his character and personality. It was a privilege to meet him.
5. I have heard from several witnesses in the course of this application this afternoon. During the evidence of Jackie Walsh, his case manager, I commented that that the conclusions reached at the July hearing in 2017 relating to the extent of MB's learning disability did not entirely reflect my experience of him. Of course, I have no way of accurately assessing this. The speed with which he was able to use the communication aids which Ms Mackintosh, his solicitor, has helped to create for him; the vitality of his responses and the charm of his humour, seemed to my mind to reveal a young man who is intellectually, cognitively, functioning at a reasonable level. I note that he had acquired significant skills historically in maths, science and in computer technology and, I have been told that he is fluent in both English and Arabic. The label attributed to him perhaps does not matter. What matters is that these aspects of his personality and functioning are all part of who MB is. I expressed my view to Ms Walsh who told me that she was exactly of the same view.
6. MB can only communicate with the outside world by blinking. I assumed, before meeting with him, that would be a significant impediment to his being able to communicate to me what he wanted to happen. In fact, though he could only communicate in this limited way, I found him to be clear, eloquent, and entirely unambiguous in the communication of his wishes. On the late Friday afternoon as I visited the St Mary's Hospital it was particularly warm. MB was, at times during the course of my visit, uncomfortable and communicated his discomfort through Ms Mackintosh, so that we withdrew from his room in order that he might be turned in his

bed. On one occasion, with his permission and that of the nurses, I stayed in the room to see what was involved. I was there, I think, in the region of an hour and half, at the end of the day. There were times when I sensed that MB was tired, but Ms Mackintosh repeatedly offered him the opportunity for a break, and repeatedly he declined it. He had no doubt who I was. He had not the slightest uncertainty about the purpose and importance of my visit and he was entirely determined, indeed dogged, that he would get his views across to me.

7. At the end of the afternoon, having watched Ms Mackintosh carefully, I spoke directly with MB myself for a few minutes. I wanted him to know what I understood him to be saying, so that I could confirm that I had understood it properly. I said to him ‘MB, this is what I believe you are telling me: that you want to go home, to your mother; you recognise that the doctors say that you are going to die; whilst you understand that, you want to live; at home, there has been a lot of conflict, but even so, you would prefer to go home. Finally, what you would most like, would be a steak.’ I remember with great clarity and I suspect will do for a very long time, that as I communicated these facts, MB’s face smoothed of wrinkles and anxiety. It was as if the stress lines had been miraculously ironed out. I was left with the very clear sense that he was satisfied that he had got across to me what he wanted to say. As I said to Mr Patel QC, in the course of exchanges, in the Court of Protection, we spend a great deal of time trying to evaluate what people would have wanted, in difficult circumstances when their capacity has gone. There may be questions surrounding MB’s capacity, but I am absolutely clear that MB’s wishes are those that I have set out above. Not unusually, perhaps even unprecedentedly I do have a scintilla of doubt about it.
8. MB’s communications are inevitably pared and direct but they do not conceal his personality in any way. Also, he finds an opportunity for what I have to call ‘a bit of banter’. I will spare his blushes by not incorporating that into this judgment. It requires to be observed however, that he is a young man who is living in circumstances that would challenge the most phlegmatic of characters but he is sanguine, determined and fighting heroically to go home where he knows that time is likely to be short.
9. Management of MB’s medical regime at home was always going to be a challenge, but to that challenge has to be factored in the relationship with his mother. She simply cannot accept that MB is approaching the end of his life. She is unable to do so. In some way she has distorted her entire belief structure, such that she cannot see this physically diminished young man, as he now is. Some of her suggested options for his care are so unrealistic that they serve only to illuminate the extent of the mother’s delusions. This is particularly indicated by her pre-occupation with a brace to enable MB to sit up. That simple joy is one that has now passed. Not only does the medical evidence make that clear but it would be obvious to anybody meeting MB.
10. During the course of evidence, I have been considering a return home on a palliative regime. This presents an enormous dilemma for the mother. On the one hand, she wishes MB to come home. But on the other, at some level, she appreciates that he is coming home to die. She has, I have been told, at least accommodated that conflict to this extent: she has been very cooperative in working towards a care plan facilitating MB’s return.
11. On the 10th June 2019, I made orders and declarations to give effect to that return. Since then, the situation has become complicated in consequence of MB sustaining a

very serious and persistent infection. That on its own may not have inhibited compliance with my order, but the fact of it, coupled with the significant bureaucratic challenges that the return home presents has, in combination, thwarted the plan. I have had to consider, this afternoon, whether, as events have unfolded, the plan continues to be in MB's interests. The persistent infection, staphylococcus epidermis, has further weakened MB. The ICU team, led by Dr Ashworth, have been treating it with Vancomycin. Following a month of treatment, the antibiotic was discontinued, in accordance with practice, but MB deteriorated very quickly following its withdrawal. Changing the venous line, the Hickman line, has not assisted in eradicating the infection and, as I understand it, in conjunction, MB's respiratory tract is also colonised with stentrophomonas (at the moment that is not pathogenic).

12. The challenge created by this situation is that continuing the Vancomycin, which has been reintroduced, will inevitably lead, ultimately, to the staphylococcus becoming resistant. Treatment with the Vancomycin in the community will be challenging, because it requires monitoring the drug levels in the blood. By way of completeness it should be said there is no other antibiotic to treat this infection and that as such, eradication of the virus, (which is 'missing', in the sense of being presently unidentifiable) is ultimately not possible. There can be no hiding from the fact that in conjunction with the other significant compromises to MB's health, this virus will eventually kill him, if he does not die of some other cause prior to that. Modern medicine creates a raft of ethical, moral, legal, philosophical challenges. Medics, like lawyers, are trained to look for certainty, for logical of outcomes; for justification of treatment. MB is, however, more than the sum of his various conditions. Though it is difficult to capture, MB is a 24 year old man whose treatment cannot be approached purely from the perspective of medical logic. Into it must be factored his own aspirations, not for how he will die, but in how he will live the remainder of his life, however long that may be.
13. In addition to the present intravenous antibiotics, I have to consider the regime of the opiates, the TPN, and the ventilator. In any circumstances, that is a complex medical matrix. I have listened to all the witnesses with care. But with particular care to the lead clinician Dr Ashworth. It struck me, if he will forgive me for saying so, that he was pulled consistently in contrary directions. His instinct as a doctor, with his obvious skill and experience, is that MB's death medically can be best managed in the hospital situation, with the wide panoply of options all at hand. However, Dr Ashworth's willingness, more than that, his preparedness to look creatively at the options in a transitional plan and return home reveal a proper determination to keep the 'whole patient' at the centre of this plan. I was left with the sense that, in his analysis, both options have a similar degree of attraction for Dr Ashworth, as well as a similar degree of disadvantage.
14. Dr Ashworth has, cautiously, but unambiguously, accepted the role of 'Responsible Clinician', in the event that MB moved to live at home. That, I am told, must be cleared by those with the appropriate administrative authority. However, I am bound to say that a lead clinician with central overall responsibility, overseeing and coordinating the plan is, to my mind, indispensable.
15. Also, integral to the plan is Dr Buxton, who has battled through the bureaucratic maze to a position where she is now able to put herself forward as the palliative care consultant with responsibility for overseeing MB's palliative care in the community. I

pause to say that it is a great pleasure to see two such experienced doctors who have been prepared to assert their medical expertise over the bureaucracy which no doubt entangles them on a regular basis. I am very clear that MB is the beneficiary of their proper assertion of professional independence.

16. And so, it has been possible to put together a care plan which is very significantly beyond the ordinary. It has required enormous ingenuity and determination, thought, reflection, debate and creative thinking. It is a triumph of professional collaboration, into which contribution must be factored Ms Walsh's own considerable input as case manager. She, I suspect more than any other, has driven this through. She has known MB for some considerable time, albeit that for reasons I need not mention, that relationship was interrupted. She diffuses the mother on a day to day basis, so that she takes the whirlwind force of her distress, in order that the clinicians can be spared it. Having experienced it myself, I am humbled to think that Ms Walsh can deal with that as she does, so many times per week and for such protracted periods. But it has been a lightning conductor, and it has enabled, in my judgment, the proposed plan to be viable. She has taken steps since my judgment to assist St Mary's to develop the care package at home to the extent that it will involve the instruction of a nursing agency 'Pulse', providing 24 hour care from two staff, a nurse and a healthcare assistant.
17. One positive feature of the delay to MB's transition home is that those staff members have now been shadowing the nursing staff on the ward at St Mary's so that they have a real appreciation of his needs and are ready to take up the responsibility. Far too frequently this kind of parallel planning breaks down usually for financial reasons. Again, it is profoundly encouraging to see such well-coordinated professional commitment.
18. Dr Buxton saw MB this morning, and was struck by a further deterioration. He has of course recently been reintroduced to the Vancomycin and he has had a variation in his opiate regime (now sub-cutaneous). Nonetheless, the deterioration, in Dr Buxton's view, is manifest. This, I have been told, is a clear and sad indication of MB's life expectancy. It is also significant feature because as he deteriorates, MB's capacity to communicate by blinking will also inevitably reduce. The nurses from Pulse will face even greater challenges in understanding his responses in the weeks ahead, specifically engaging the extent of pain relief.
19. I have not laboured in this judgment to set out the extent of the mother's behaviour. It is unnecessary to do so, other than to say that it has frequently been inimical to MB's best interests and to his welfare. Many would have flinched at the prospect of a return home, in the context of a mother capable of causing such disruption, and who simply refuses to believe the reality that we are approaching the final stages of MB's life. But MB knows his mother. He knows she is not prepared to accept the reality. In my assessment of what others have said about him and what I have seen myself, he has factored this into his own decision. He told me in clear terms that he knew there would be conflict. He illustrated that, through Ms Mackintosh, by reference to angry faces in the communications book, but it didn't make any difference: he still wanted to go home. When Ms Mackintosh visited MB most recently on 2nd July 2019, he again clearly stated his wish to return home, and to return home quickly. He did this by reference to the image of a running hare under which is the word 'fast' in his communication book.

20. MB has a resilience. He has lived much of his life in conflict. He has in each of the past six years been the subject of litigation about which he is fully aware. I would like to think that today would be the last time that his case is litigated. But whilst, as I say, many would flinch, Ms Walsh has not done so. She has provided security backup from a specialist contact agency called Project West: that is an organisation which judges in the Family Division in which I also sit will be aware of. At first blush, it sounds rather intimidating. But I have been told it is a highly specialist service, where the agents are carefully trained in diffusing and calming challenging situations.
21. Ms Walsh tells me that this is the only time in her career that she has provided for such an agency. Her knowledge and her understanding of MB leads her so firmly to conclude that a good death for him will only be at home, as to drive her to take this extraordinary and unprecedented measure. Finally, community palliative nursing has been provided by an outside agency, Pembridge palliative care, whose staff are known to Dr Buxton, and with whom she is satisfied that in consultation, she can meet MB's palliative care needs.
22. Thus, the plan is there, not merely in outline, but in careful detail. There is only one outstanding issue, and that is whether in his return home, MB should have the TPN in situ. The answer to this I leave to the professionals, if necessary, I will resolve it. But I hope I don't have to. Because it is an issue that ought to be resolved in the same way that I have tried to address the bigger issues here, by considering the TPN in the context of the broad canvas of MB's welfare and medical needs. It is not a bureaucratic matter, it is a medical welfare matter, and must be resolved on that basis.
23. Accordingly, as I hope the logic of my reasoning has made clear, I have concluded that the plan to return MB home which I first thought to be the correct course indicated now as long ago as the 10 June, remains not only a viable option but the best option for MB. In coming to this conclusion, I have of course considered the extent of his wishes and feelings, the depth and duration of them, but they have not, and it requires to be emphasised, been determinative. They are part of the wider landscape of factors. What ultimately has persuaded me that the plan is sustainable is the commitment of the doctors and the professionals I have identified, who have been so determined to make it work. It remains in his best interests, and I declare so accordingly.
24. I will also declare that backup ventilation should be switched off, at a time determined by Dr Ashworth, unless there is identified any medical reason contrary to that.
25. As to the backup ventilation, I will declare that it should be switched off unless there is identified any medical reason contrary to that. Having listened to the evidence I have concluded that the antibiotics should be withdrawn prior to discharge, having been satisfied that they are unlikely to facilitate a greater period of lucidity in the event that they were continued for 48 hours after MB's return. As to the withdrawal of the BiPAP ventilation support once he is at home, that will be a decision ultimately for the responsible clinician at the end of the day, in collaboration with all those around him. I am entirely confident, having listened to Dr Ashworth break down the variety of clinical options, that at the end of the day, that decision should be left to him in consultation with his colleagues. I would very much hope that the mother could be involved in these discussions in a meaningful way. The history of the case gives me little hope that this will be possible. This brave young man, who has lived his entire life with profound

disability and much pain has, if anybody can, earned his right to a peaceful death at home with those he loves.

Best interests:

26. As I have said in a number of cases the legal framework is relatively easy to state though always difficult to apply in sensitive cases at the end of life. I do not consider an exegesis of the law is required here. Indeed, again as I have commented before, the exercise risks eclipsing the lode star which guides the Courts approach i.e. the best interests of the patient. It is always important however, to emphasise that the assessment of best interests should not only involve medical factors but should be holistic *Aintree NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 519; *Wye Valley NHS Trust v B* [2015] EWCOP.
27. The clearest encapsulation remains that of Baroness Hale in *Aintree NHS Foundation Trust v James* (*supra*) namely:

"[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."