

Neutral Citation Number: [2020] EWHC 2595 (Fam)

Case No: FD20P00507

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 28/08/2020

Before :

THE HONOURABLE MR JUSTICE HAYDEN

Between :

**Birmingham Women's and Children's NHS
Foundation Trust**

Applicant

- and -

JB

1st Respondent

- and -

KAB

2nd Respondent

Ms Nageena Khalique QC (instructed by **Capsticks Solicitors LLP**) for the **Applicant**
Victoria Butler Cole QC (instructed by **Official Solicitor**) for the **JB**
Mr Parishil Patel QC (instructed by **Irwin Mitchell**) for **KAB**

Hearing dates: 28th August 2020

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 open court, by way of a video conferencing platform and was attended by the press. 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 child 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.

Mr Justice Hayden :

Preface

On the 28th August 2020 I heard an application made on behalf of the Birmingham Women's and Children's NHS Foundation Trust. The case was heard by way of video conferencing platform to which the public had access and the press were present. As is set out below, the family concerned were gathered together, listening to the evidence. It was very clear to me that they required the decision to be made that day, as well as to understand something of the reasoning that underpinned it. With that in mind I delivered an extempore judgment. Counsel were able to take a thorough and accurate note of it and I have now perfected it, in accordance with the conventional principles in *Piglowska v Piglowski* [1999] UKHL 27. In addition, I have added a post script.

1. This is an application brought by the NHS Trust relating to J. J is a 12-year-old young person who has acquired a severe brain injury. The application made by the Trust is for a declaration sanctioning the withdrawal of intensive care and effectively confirming the absence of any alternative procedures which might otherwise be thought to be in his best interests.
2. It is a case of almost unbearable sadness. J was found hanging with a ligature around his neck on the back of his bedroom door on 28th April 2020. His mother was at home and reported that he had been in his bedroom for no more than 20 minutes when he was found and cut down by his family. An ambulance was called immediately, and the ambulance call handler talked J's mother through the mechanics of basic life support. The paramedics arrived at J's home within 6 minutes. He received bag valve ventilation, two doses of adrenaline and spontaneous circulation was recovered. The documented 'arrest time' for the heart is stated as 13 minutes, with a potential of up to 20 minutes before he was found, on the history given. This gives a total maximum arrest time of over half an hour. J was attended by the MERIT ambulance crew who are trained in intensive care. It was possible to intubate him at the scene using rapid sequence induction. He was taken from there to the hospital. When he arrived, he was sedated, he had spontaneous circulation and he was ventilated.
3. Immediately, J was taken for CT scanning of the brain and cervical spine. I have seen a number of radiology reports outlining the condition of the brain. The most recent of these was that of 29th July 2020 which revealed consistent cerebral deterioration. In summary, the brain shows diffuse reduction in cerebral grey/white differentiation, there is no effacement of the basal systems, no fracture/dissection, the scan shows evidence of damage from a lack of oxygen. The scanning has, as I have indicated, shown clear and distinct deterioration in the months that J has been in hospital.
4. Dr B of Birmingham Children's Hospital provided a report in these proceedings, dated 12th August 2020. In that report he was interpreting the CT imaging of J's brain, undertaken on 9th June 2020. In a way which I have certainly found to be helpful and I hope the family did too, Dr B explained the cerebral anatomy in simple language and outlined what, in practical terms, the atrophy to J's brain means in the context of any future treatment.
5. The most prominent damage to the brain is in four regions. Firstly, the perirolandic area. This is the outer layer of the brain, the cortex, and it comprises the frontal lobe

and the frontal part of the parietal lobe. It is the part of the brain that would have allowed J to move his body and to detect and receive and respond to touch. So significant is the damage to this area that J is not able to respond to touch in any way.

6. The parietal lobe was also damaged. This is the outer layer of the brain and is the area that receives and co-ordinates sensations from the body. Damage here makes it hard or impossible to sense when you are touched or to move your limbs or even to know if somebody else is moving your limbs for you.
7. The occipital lobe was also catastrophically damaged. This is the area that governs the visual processing faculties of the brain which facilitate sight. The severity of the injury to both the occipital lobes has caused profound visual damage, leading to J becoming blind.
8. Finally, there is damage to the basal ganglia. These are much deeper structures in the brain, they are involved in co-ordinating movement and sensation. A severe injury to both basal ganglia regions, as seen here, will leave a person with profound stiffness and an inability to co-ordinate their movements.
9. Dr A is the paediatric intensive care specialist at the Trust. She has been involved in J's care since 2nd May 2020. She was not involved with his initial admission. In addition to her report and that of Dr B I have read the statements of Professor C, consultant paediatric neurologist. I have also read an independent medical report prepared by Dr D, a consultant intensivist. As all the parties recognise, there is a complete consensus amongst all the consultants both as to J's present condition and the futility of his prognosis. It is important that I state, in unambiguous terms, that J's family recognise the strength and cogency of this evidence.
10. I was able to hear evidence, on a video conferencing platform, from Dr A, who articulated the professional consensus. She has been the first point of call for the parents since May 2020 and as I have watched the family via the video link and listened to Dr A giving her evidence from the hospital, it has become obvious to me that there is intense respect here, each for the other. Whilst the Trust's application is resisted, this is not a hearing characterised by conflict. On the contrary, the prevailing mood is one of kindness, empathy and profound sadness. I was impressed and moved by Dr A's energy and commitment to J. Her care for him and her sensitivity in her relationship with the family, illustrated a fondness and affection for this young man which went beyond the merely medical.
11. I was left with no doubt at all that Dr A and indeed all those involved in J's care were prepared to do anything that could conceivably be done to help him or in any way to improve his parlous situation.
12. Despite the return of cardiac output, J has suffered a profound and severe hypoxic ischaemic insult to his brain which I am satisfied can properly be characterised as being at the most severe end of the spectrum. J does not fulfil the criteria for brain stem death, but he has a profoundly severe neurological injury. In her evidence and report, Dr A describes it in these terms at paragraph 13:

“The neurological injury is manifest by unconsciousness. The GCS of 3-6 and the inability to keep his airway clear without an endotracheal

tube, means that he requires regular suctioning of the back of his mouth and throat where secretions gather. J shows no spontaneous movement and no cerebral response to deep central painful stimuli either by clinical observation of movement or by neurological monitoring.”

13. J has been monitored by nurses and doctors 24 hours a day, 7 days a week since his admission. I agree with J’s father that they have been inspirational in the care that they have offered.
14. There was an occasion which Dr A identified in her report where she noted that the committed and experienced nurses thought that there was a possibility that J might have been responding to painful stimulus. Dr A was prepared to contemplate the theoretical possibility that there is some perception of pain that the clinicians are unable to detect. Dr A was asked whether J’s situation could properly be described as his being unable to experience pleasure but nonetheless able to experience pain.
15. In simple, measured language, Dr A responded that it is very, very unlikely that J can experience pain. J has no controlled eye movement. Periodically, throughout the day and night he opens his eyes. He demonstrates spontaneous abnormal posturing with spasms of upper and lower limbs. The medication administered to counter this has not been effective. J’s leg has been weighted to minimise the impact of the spasms. Those spasms affect his chest wall and upper airway and make it difficult for him to breathe independently. As a result of his brain damage, he has lost the reflexes, which Dr A told me a new-born child would have, to protect his airway and gag reflex.
16. Clinical staff have shared and explained this information with J’s parents and wider family. The intensity of this tragedy is, as I said at the beginning of this judgment, unbearable. It arises in the circumstances of a global pandemic with all the additional challenges to the family and the medical staff that this unprecedented public health crisis has brought. There are, I think, facets of human suffering that are so intense, they defy empathy. There is a level of distress from which the human instinct is to recoil rather than confront such visceral pain. During the course of the last few months there was a point at which J contracted Covid 19. This was unpreventable and illustrates only the insidious and highly infective nature of this virus. The consequence was that for two weeks only J’s mother and no-one else in the family was able to visit. In the weeks that followed, because of the inevitable and necessary restrictions, family members were not able to visit together in the way that they were desperate to. For J’s father not to be able to see his son for those 14 days is completely heart-breaking. His distress, particularly at an earlier directions hearing, was harrowing and will be long remembered by those of us who witnessed it.
17. Each breath that J takes requires augmentation by the ventilator. In early May, J managed a few days without positive pressure from the ventilator and a ‘Swedish nose humidifier’ was attached. That simulates the process of breathing with a tracheostomy. J’s breathing became more irregular in pattern.
18. As Dr A told me in her evidence, this was, in effect, a trial to see whether a tracheostomy might be possible. The sad conclusion was that it was not. Later with his parents’ permission and encouragement, a trial period of extubation was undertaken, on 27th May 2020. That must have been an extremely difficult day for this family. J managed

approximately 13 hours breathing spontaneously with a nasopharyngeal airway. But this failed after 13 hours, triggered by the muscle spasms which have not been possible to control, coupled with secretions in the airway.

19. One of the opportunities that has been afforded to me in the “remote hearings” that the court has been conducting, during the course of this continuing pandemic, is that I have been able with the assistance of doctors and nurses both in this court and in the Court of Protection, to visit patients, to a degree that would not always have been considered as a possibility in the past. J, it must be remembered, is in a deep coma.
20. My view, and I entirely respect that others may have different perspectives, is that when making decisions of this magnitude there are subtle, intangible, and unpredictable benefits for the judge in seeing the individual in respect of whom he or she is required to take such Solomonic decisions. I visited J, via video link, with his Guardian, Ms E and with Dr A. Unexpectedly, when we visited, J’s brother was present. He told me he was sometimes able to ‘dodge’ security and get in. I sense his presence was very much welcomed by the nurses and the staff. As he was there, I spoke with him about his brother. Later, I relayed this to the family. He was very proud of his talented, fit, determined young brother J. He told me that J is “*a fighter*.” It is clear from the history I have set out above how J’s brother’s view is supported by J’s resilience in ITU.
21. J is deeply loved by his entire family. Their love for him is almost palpable, communicated compellingly, even in the artificiality of these remote hearings. In April of this year, J was a young boy full of talent, thriving in his studies, enthusiastic about science and, I have been told, a fearless and committed midfielder with a very real prospect of future professional football emerging for him. J’s father took obvious pleasure and pride in his son’s footballing prowess. Nobody has identified any reason at all why, on 28th April 2020, in that short period away from his family, J made an attempt to take his own life. This has not been explored at this hearing, it was not necessary to do so, the focus has been on J’s wider experiences in life and his undoubted personal strengths.
22. J is, as I have said, mechanically ventilated. When the ventilator is disconnected, and the endotracheal tube is removed, he will continue to breathe but his muscle spasms will, inevitably, impede regular breathing. There is no evidence that J is in pain or discomfort, but Dr A told me that upon disconnection of the ventilator it may, nonetheless, be appropriate for opiate medicine to be administered in order to minimise the distress to the family witnessing the continuing spasms. One further element in the reasoning behind the plan to provide opiate relief was to promote and protect J’s dignity at the end of his life. The breathing pattern may be distressing for his parents and ultimately will cease. It is conceptually difficult either to identify or define human dignity in circumstances where the person at the centre of concern has no appreciation or recognition of his own situation. Difficult though it is, I am clear both that it exists and that committed dedicated medical staff have an instinctive appreciation of it and a determined resolve to protect it. However distressing J’s situation is, it was obvious to me when I visited him, unexpectedly finding his brother along side him, that all involved in J’s care were determined to do their very best for him and from their different perspectives were each driven by the highest of motives. This, in my judgement, conferred dignity on this young man.

23. I am satisfied and I do not need to outline in this judgment, not least because I have touched upon it already, that the limited and hypothetical alternatives to ventilation have been explored. Treatment is providing no benefit for J. The burdens of the treatment are obvious. The tube itself has every capacity to cause irritation in the mouth and lips, the complications surrounding loss of cough and gag reflex render the airway vulnerable, J has muscle spasms, which I saw on my visit, and which have already threatened to cause muscle breakdown. He is at risk of acquiring chest infections from prolonged ventilation. Also present when I visited was one of his nurses. I know the parents will join me in saying all the nurses have attended with sensitivity and vigilance to their son's care. J has remained entirely without pressure sores because 3 nurses over many months have turned him solicitously and attentively every 3 hours, applying cream and *'keeping him comfortable.'*
24. Dr A was satisfied (see para 15 above) that it was extremely unlikely, in view of J's deep coma, that he was suffering pain or distress. He has lost cognitive function. He has lost the ability to continue a relationship with his family. He is unable to experience pleasure. It is not possible to provide continued mechanical ventilation or to provide a tracheostomy given the problems associated with prolonged ventilatory support.
25. The prospects for J's life, I am satisfied, can properly be described as futile. That means simply this, that the damage to his brain is so extensive and widespread that he will not make any recovery from this awful episode. Keeping J alive will achieve no benefit and serve only to protract his burden.
26. I reiterate, I was impressed by Dr A's evidence as well as her relationship with her patient and the family. She also encapsulated the professional ethical dilemma that she perceived. *"The time has come"* she said where *"I am no longer saving J's life, I am prolonging his death."* She identified this as ordinarily counter intuitive to her as a doctor and contrary to what she would usually perceive to be her ethical medical responsibility. Her phrase distils the central challenge of this case.
27. I have on more than one occasion described the applicable law in cases such as this as being easy to state but intensely difficult to apply. There are a number of key judgments analysing the law in this area. But none I think add to the words of Baroness Hale in **Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67, [2013] 3 WLR 1299** (para 39):

"...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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be."

28. The objective remains to identify what is right, what is the best course for J. Dr A considered that the intrusive nature of J's treatment when evaluating the bleakness of his prospect for survival risked compromising his dignity.
29. Ms Butler-Cole QC who appears on behalf of the Guardian has referred me to a commentary in the Medical Law Review from 2019: **Making Decisions for Children— Accommodating Parental Choice in Best Interests Determinations: Barts Health NHS Trust v Razeeb [2019] EWHC 2530 (Fam); Razeeb and Barts Health NHS Trust [2019] EWHC 2531 (Admin) Cave, E; Brierley J; Archard D. Medical Law Review, Vol. 28, No. 1, pp. 183–196.** She highlights the authors conclusion:

“What concerns us in this case is not that a court can overrule the clinical view of overall best interests. That potential is the very purpose of the hearing. Rather, our fear is that the interpretation of the best interests test in Razeeb raises the potential for Trusts to conclude that professional obligations to the child can be secondary to those to the parents. This flows from a novel approach to best interests in the judgment including the separation of medical and overall best interests; the recognition of the relevance of international laws and frameworks to best interests determinations, notwithstanding their potential conflict with national judgments and professional guidelines; and reliance not on what Tafida could understand and express but on what she might in future have come to believe had she followed her parents’ religious beliefs.”

30. I am confident that Macdonald J, in **Barts Health NHS Trust v Razeeb [2019] EWHC 2530 (Fam)** did not for a moment intend that a Trust should ever approach an evaluation of a child's best interests, in the context of medical treatment, as secondary to the wishes or religious beliefs of the parents. That would subvert the framework of the established law which preserves the interests of the child as paramount. Nor do I believe Macdonald J intended to sever medical 'best interests' from an overall evaluation of the child's interests. Such an approach would be artificial. A true and meaningful assessment of a child's best interests requires a conscientious survey of the wide canvas of his life, in which process the views of his parents concerning matters of faith, culture and more widely will be important but never a determinative factor. The anxieties expressed in the Medical Law Review article (above) can therefore be dispelled as an incorrect understanding of the applicable law.
31. In **Wyatt v Portsmouth NHS Trust [2006] 1 FLR 554** at paragraph [87], the Court of Appeal held that there were six 'intellectual milestones' for a judge making such a decision:

“In our judgment, the intellectual milestones for the judge in a case such as the present are, therefore, simple, although the ultimate decision will frequently be extremely difficult. 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 (Re J). There

is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable (Re J). The term 'best interests' encompasses medical, emotional, and all other welfare issues (Re J). The court must conduct a balancing exercise in which all the relevant factors are weighed (Re J) and a helpful way of undertaking this exercise is to draw up a balance sheet (Re A)."

32. In **Re J (a minor) (Wardship: Medical Treatment) [1991] Fam 33** Lord Donaldson of Lynton made the following observations, which have weathered the test of time (at page 43):

"There is without doubt a very strong presumption in favour of a course of action which will prolong life, but ... it is not irrebuttable ... Account has to be taken of the pain and suffering and quality of life which the child will experience if life is prolonged. Account has also to be taken of the pain and suffering involved in the proposed treatment... We know that the instinct and desire for survival is very strong. We all believe in and assert the sanctity of human life Even very severely handicapped people find a quality of life rewarding which to the unhandicapped may seem manifestly intolerable. People have an amazing adaptability. But in the end there will be cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause it increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's, and mankind's desire to survive."

33. The Pentecostal church is at the core of this family's life. Its beliefs are the code by which they live their lives. Having had the privilege of hearing from members of the family, it is easy to see how faith is entirely integral to their daily activities. They are kind, hardworking, respectful to each other and to those with whom they come in to contact. They told me that J also had a strong sense of duty to others and to the wider community.
34. I am told that J held fast to these Pentecostal beliefs and I note that the family, in what we have come to know as 'lockdown', were assiduous in participating in the 'remote' congregations of their church. I recognise that whilst those remote services would have been important to them, they each would have been deprived of the physical solace and comfort of their friends in their church community. This coupled with the necessary restrictions on their contact to J must have stretched them to the limits of their emotional endurance.
35. The family have not sought actively to challenge the medical evidence. Indeed, it is right to say that they recognise the force of it. The hospital instigated a further independent review which, as I have indicated, came to the same conclusion. The family has not sought to avail itself of the arguments touched upon at paragraph 29 above. They, instinctively to my mind, identify the paramountcy of J's best interests as the appropriate applicable criteria upon which to make this decision. What this family does, is to counter the medical evidence with their faith. In effect they seek time for a miracle.
36. Just as the family has been respectful to the doctors and medical staff, so too has that respect been returned. With the loosening of social distancing restrictions and

diminution of pressure on the NHS, the hospital was able to facilitate a week of intensive prayer by J's bedside.

37. In this case I have not been prepared to investigate what J might have wanted for himself in the circumstances he now finds himself. The views and wishes of a child of 12, extrapolated from the facts surrounding the way he lived his life and the views he has expressed, would in many circumstances be an appropriate and indeed necessary enquiry. Here however, the sad facts leading up to J's admission to hospital leave only unanswered questions. I am certainly not prepared to infer that J's attempt on his own life would mean that he would wish treatment to be withdrawn. For the same reason the counter veiling assumption that J's faith might indicate a spiritual resistance to withdrawal of life support is also one I am not prepared to make.
38. The Pastor who conducted the week of prayer has attended at court with this family. That he has been a tower of support to them is manifest. Though I did not hear evidence from him he told me, from the conferencing platform where the family were collectively gathered, that the family respected the challenge the court faced and would accept its conclusion. The Pastor volunteered his recognition that everybody involved was trying to do the right thing for J. J's father had foreshadowed those sentiments in his own evidence.
39. I consider that the evidence provides compelling support for Dr A's ethically rigorous conclusion that we have reached a stage at which treatment is prolonging J's death and not saving his life. The growing therapeutic possibilities of medical science have made it possible to eliminate many diseases and to prolong people's life span. The present global pandemic is a stark check on the limits that remain. Nonetheless, whilst many developments have proved immensely positive it must be confronted that it is now possible to extend life by means and to an extent that were simply inconceivable only decades ago. Effective medical intervention must not be conflated with beneficial intervention. Artificially sustaining vital organs that have failed is not, in my judgement, the same as promoting life. The desire to maintain and promote what is often referred to as the 'sanctity of life' runs deep in human morality. This is in no way inconsistent with a recognition that there comes a point, in some cases, whilst though nobody would wish to cause or hasten death, there emerges a mature and morally responsible recognition that it can no longer be impeded. This is acceptance. It acknowledges the limitations of our human mortality and recognises that opposition to death reaches a point where it becomes futile. These are not easy decisions for doctors in today's medical context nor is it ever an easy decision for the judge. There is here between the doctors and the family an underlying recognition of the importance of preserving human dignity. Thus far that has been achieved for J, notwithstanding the many challenges created by Covid 19 restrictions. Further to prolong his present situation would, I am satisfied, risk compromising his dignity and for no identifiable benefit. For these reasons I have been able to grant the declaration that the Trust seeks from me today.

Post Script

I have now been informed that J died peacefully, surrounded by his family. The Pastor was present when J's treatment was withdrawn. I have sent my own sincere condolences to the family and to the medical staff.