

Neutral Citation Number: [2015] EWHC 2828 (Fam)
IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice

Friday, 2nd October 2015

Before:

MR JUSTICE HOLMAN
(Sitting throughout in public)

B E T W E E N :

CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST
Applicants

V

A and others

Respondents

(Withdrawal of life support)

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(a trading name of Opus 2 International Limited)
Official Court Reporters and Audio Transcribers
5 Chancery Lane, London EC4A 1BL
Tel: 020 7831 5627 Fax: 020 7831 7737
info@beverleynunnery.com*

MS LORRAINE CAVANAGH (instructed by Hempsons) appeared on behalf of the applicant NHS Trust.

MS MELANIE CAREW (of Cafcass) appeared on behalf of the respondent children by their guardian.

THE FATHER, Mr A, appeared in person on behalf of himself and his wife, the childrens' mother.

J U D G M E N T

MR JUSTICE HOLMAN:

Introduction

1 This case concerns the withdrawal of life support from two very young children. No one, which includes myself, who has not been in the position of the parents in this case can possibly truly appreciate and understand the agony with which they are faced. I have the utmost respect and sympathy for them in their plight. The mother has not personally attended this hearing. Her husband, the father, has done and has represented both parents in person. Although his command of English is limited and he has communicated mainly through an interpreter, he is, if I may very respectfully say so, a man of obvious intelligence and insight. He has participated in this hearing with intelligence, a complete grasp of the issues, moderation in his approach, and, I would add, considerable personal charm. Further, the evidence from the doctors, and also my own observation of a short video which the father showed me on his mobile phone earlier today, is that the father, and I am sure also the mother, care for these two boys with very great tenderness.

2 The issue in this case is whether it would be lawful to withdraw mechanical or artificial ventilation from two identical male twins, now aged about fourteen months. Being identical or monozygotic, their genetic make-up is identical. They both suffer a progressive neuro-degenerative disorder. It has no known

diagnosis and is untreatable and completely incurable. If the mechanical ventilation is withdrawn from either of them, he will inevitably die, probably within an hour or two, being unable to breathe naturally. This situation has persisted now for several months. The treating medical team consider that it is unethical to maintain the ventilation and that they are now needlessly prolonging pain and suffering for each boy. The parents, very, very understandably, feel unable to consent to the ventilation being withdrawn.

- 3 The applicant NHS Foundation Trust now apply to the court for a declaration that it would be lawful and in the best interests of each child to withdraw or discontinue the ventilation, despite the lack of parental consent. The treating team have made very clear that if I do grant that declaration, they would wish to engage fully with the parents, whom of course they know very well, as to the manner in which the process would be handled. For instance, whether the ventilation should be withdrawn at the hospital or at a hospice or, if the parents so wish, at their home; and whether it should be withdrawn from both boys at the same time or sequentially and, if so, in which order. As the treating paediatrician said, the hospital is, very sadly, used to handling such situations. I have no reason at all to doubt (nor is it disputed by the father) that the sad process would be handled as humanely, sensitively and sympathetically, and with as much dignity, as possible.

4 I hope it goes without saying, but needs to be stressed and made express, that each boy is an entirely independent human being in his own right, and each requires separate consideration. If there was the slightest relevant difference in their development, functioning or prognosis, that could be absolutely critical, and the doctors have stressed that at all times they treat and consider each child separately and individually. That said, the truth is that these identical twins suffer the same identical disorder. It is equally severe in both of them; and frankly there is no material difference between them, although the precise progress of the disorder may vary between the one or the other from one day to the next.

The law

5 As relatively long ago now as March 2006, in the case of *An NHS Trust v. MB* [2006] EWHC 507 (Fam), I endeavoured to summarise the legal framework in a situation such as this in ten propositions which I set out as (i) to (x) within paragraph 16 of my judgment. So far as I am aware, the law has not changed. Those propositions have been frequently repeated, and have never, so far as I am aware, been criticised or stated to be wrong. I therefore now repeat them:

“(i) As a dispute has arisen between the treating doctors and the parents, and one, and now both, parties have asked the court to make a decision, it is

the role and duty of the court to do so and to exercise its own independent and objective judgment.

- (ii) The right and power of the court to do so only arises because the patient, in this case because he is a child, lacks the capacity to make a decision for himself.
- (iii) I am not deciding what decision I might make for myself if I was, hypothetically, in the situation of the patient; nor for a child of my own if in that situation; nor whether the respective decisions of the doctors on the one hand or the parents on the other are reasonable decisions.
- (iv) The matter must be decided by the application of an objective approach or test.
- (v) That test is the best interests of the patient. Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. These include, non-exhaustively, medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.
- (vi) It is impossible to weigh such considerations mathematically, but the court must do the best it can to balance all the conflicting considerations in a particular case and see where the final balance of the best interests lies.
- (vii) Considerable weight (Lord Donaldson of Lynton MR referred to 'a very strong presumption') must be attached to the prolongation of life because the individual human instinct and desire to survive is strong and

must be presumed to be strong in the patient. But it is not absolute, nor necessarily decisive; and may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering or other burdens of living are sufficiently great.

(viii) These considerations remain well expressed in the words as relatively long ago now as 1991 of Lord Donaldson of Lynton in *Re J (A minor) (wardship: medical treatment)* [1991] Fam 33 at page 46 where he said:

‘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.’

- (ix) All these cases are very fact specific, i.e. they depend entirely on the facts of the individual case.
- (x) The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.”

6 I wish also to incorporate by reference what I set out at some length in paragraphs 18 to 24 of my judgment in *MB* with regard to a perceived distinction between withholding and withdrawing artificial ventilation or other forms of life support. Several times in the present case the father has said that to withdraw the artificial ventilation, now that it has been commenced, involves killing the child. I completely understand how he perceives it that way and, indeed, that may be the viewpoint also of his Islamic faith. However, as the several passages which I quoted in those paragraphs make clear, there is,

and can be, no legal (nor indeed ethical) distinction between a decision to withhold artificial ventilation and a decision to withdraw or discontinue it once started. In neither case does the decision involve killing the child. The child is not killed. He dies because of the natural result or effect of his underlying disorder or disease.

The facts and evidence

7 The family is an Iraqi family who were living in Iraq. The parents have an elder son, now aged 4, who is healthy and normal. They next had a baby daughter who, very tragically, died at the age of eight months. Her condition was not fully diagnosed; but, like that of these boys, it manifested in seizures and respiratory failure, and it now seems very likely that she and they were afflicted by the same, unknown, genetic disorder. These boys, A and H, were born in Iraq by emergency caesarean in early August 2014. They initially appeared to be entirely normal babies and to develop entirely normally. In December 2014 the parents travelled with their three children to England, where the mother is undertaking a course of study. Around the age of three to four months both babies began to display abnormal features. They ceased to feed well. They displayed abnormal jerking movements. Both boys were first admitted to a hospital in England in mid-January 2015 when aged five months, and they have remained in hospitals ever since. In early April 2015 A went into cardio-respiratory arrest and required CPR for six minutes. He was

intubated and placed on mechanical ventilation, and transferred to the paediatric intensive care unit at the Royal Manchester Children's Hospital, where he has remained ever since. A few days later H was also transferred to the same hospital, so that both boys could be together. In mid-May 2015 H also suffered a respiratory arrest and has required mechanical ventilation ever since. Both boys have deteriorated ever since, although there are fluctuations from day to day in the condition of H.

The medical evidence

8 The treating doctors at the Royal Manchester Children's Hospital sought a completely independent second opinion from a consultant paediatric neurologist based in Leeds, Dr Helen McCullagh MRCPCH. The opinion of Dr McCullagh as to the deteriorating condition of the boys, and as to the futility of continuing artificial ventilation, in fact accords entirely with that of the treating doctors. As a result, I have written evidence and have also heard oral evidence from the following three doctors: Dr Stephen Playfor DM, a consultant paediatric intensivist, who is in overall charge of the treating team at the Royal Manchester Children's Hospital; Dr Mary Hughes FRCPCH, a consultant paediatric neurologist based at, and part of the treating team at, the Royal Manchester Children's Hospital; and Dr McCullagh, to whom I have already referred. In her report dated 5th June 2015, made for the purpose of these proceedings, Dr Hughes concludes:

“Regrettably, A and H have a progressive condition for which there is no treatment other than management of symptoms. A’s condition has already progressed to a stage where he is dependent on life sustaining treatment...In A when death is inevitable and prolongation of life by life sustaining medical treatment is of no overall benefit...it is the unanimous view of the treating medical team...that A should continue to have symptomatic treatment, but life sustaining treatment (ventilation) should be withdrawn...It is the unanimous view of the treating team that prolongation of life by life sustaining treatment is of no overall benefit to H and is burdensome for him and that symptomatic relief should be continued, but life sustaining treatment (ventilation) should be withdrawn...”

- 9 The earlier second opinion of Dr McCullagh was not obtained for the purpose of, or made in the context of, these proceedings, but was, as I have described, a second opinion from an outside consultant to the treating team at the Royal Manchester Children’s Hospital. Her letter, dated 15th May 2015, says in part as follows:

“Both boys have developed progressively increased tone which has progressed over time, with significant dystonic movements and the boys go into extensor spasm when handled. Both boys have continuous

involuntary movements which are described as jerky in quality and are not felt to have an epileptic origin. The boys are unable to feed orally, having lost their ability to swallow safely; neither is able to manage their oral secretions. A has had repeated episodes of apnoea and bradycardia since being on the unit and requires very frequent disconnection from the ventilator and hand bagging in order to improve oxygenation.

On examination today A was an in-patient on the Paediatric Intensive Care Unit. He was nasally intubated with an endotracheal tube. He has an abnormal posture and tone lies with his lower limbs extended and stiff, his upper limbs are flexed. His tone is variably hypertonic and he had repeated extensor spasms whilst handled. These were not associated with significant desaturations today. He is microcephalic. His head circumference is well below the 0.4th centile. This is an acquired microcephaly. He was not able to fix or follow. He did not flinch to menace. His pupils were small and minimally reactive...Both twins also had hypercalcaemia with hypophosphataemia. He had very frequent jerky movements affecting his head, upper limbs and lower limbs which were not associated with desaturation episodes. He has had an EEG which confirms that these movements are not epileptic in origin. He displayed no purposeful movements.

On examination of H, he again was microcephalic with a head circumference of 41.6cm (well below the 0.4th centile). Weight is on the second percentile and length on the ninth percentile. He was lying with an abnormal posture with arms flexed and legs extended and had episodes of facial grimacing dispersed with smiling, which I do not believe were in response to being spoken to or handled. His eyes were open, pupils were equal and reactive to light and he had no ptosis or ophthalmoplegia. He again had repetitive jerking movements. His tone was variably increased and reflexes were easily elicitable. He displayed no purposeful movements...”

Dr McCullagh then records the outcome of various neuro-metabolic and other investigations upon the boys. She continues that MRI scans have shown cerebral atrophy. She concludes:

“In summary, there is little doubt that the boys share the same undiagnosed, neurodegenerative disorder and it is likely that their sister also had the same disorder. The clinical symptoms have been relentlessly progressive to date, as evidenced by loss of development, loss of bulbar function, progressive microcephaly, cerebral atrophy and development of respiratory insufficiency. A treatable underlying cause has been excluded. Continued progression of the disease and early death

is likely. In this context continued treatment with mechanical ventilation is not in the best interests of the children.”

- 10 Although that report is dated as long ago as 15th May 2015 and was based on an examination of the children by Dr McCullagh shortly before that date, the evidence of the treating doctors, Dr Playfor and Dr Hughes, is clearly to the effect that, as predicted by Dr McCullagh in that report, the boys have continued relentlessly to deteriorate.

- 11 Dr Playfor gave extensive oral evidence, partly last Tuesday, and again when this case (which could not be heard during Wednesday or Thursday) resumed today. He said that there has been, and can be, no diagnosis of a disorder except that there is a progressive neurodegenerative process in both boys. He said that each has displayed a slow and steady loss of neurological function. Each displays underlying problems of stiffness, dystonia (i.e. abnormal tone and being abnormally stiff) and spasms. These have become progressively worse in both boys. He said that none of the treating or nursing staff have noticed any response in either boy to voice or other stimuli. He stressed that both boys are now suffering burdens, pain and discomfort, both from their underlying disease or disorder and also from the treatments being given to them. He described those burdens, but, for the purposes of this judgment, they are all summarised in a document prepared by Ms Lorraine Cavanagh, counsel on behalf of the applicant Trust, which, with her permission, I will incorporate

at a slightly later stage into this judgment. Dr Playfor said on Tuesday, which he repeated again today, that the effect of the neurodegeneration is that each child is increasingly less able to express discomfort. He said that there is a continuing decline in the neuro-functioning of each of them. They do not look at one, do not fix their eyes, and do not follow people's eyes. He said they display no evidence of any pleasure or enjoyment of life. He stressed that, if the artificial ventilation is maintained, the underlying condition will continue to deteriorate. The burden of artificial ventilation will increase. In time, their chests will collapse because of their inability to clear secretions. He stressed again that, as the illness progresses, each will become less able to display or express discomfort and pain. He said that the boys could survive physically for years with artificial ventilation and all other supportive measures. As they are being fed with nasol-gastric tubes, they will physically grow and lengthen, but their brains will not grow and develop as they should. They will remain small and will become proportionately smaller.

12 Several months ago MRI scans were undertaken on both boys. The father has repeatedly asked during this hearing whether those scans could be repeated to see if there is evidence of any brain growth. However, Dr Playfor described very clearly that there was no clinical indication or justification for repeating the MRI scans. He said that that would not assist in the treatment of either boy. Such scans may show that the brains look similar or even have enlarged in size, or may show deterioration, but that information would not impact on

the treatment of either child, for there is no correlation between the MRI appearance of the brain and how it is functioning. This point with regard to the futility of repeat MRI scans was repeated also in their oral evidence by Dr Hughes and Dr McCullagh. Dr Hughes said that both boys suffer from brain atrophy and there is no treatment for brain atrophy. She said that she would very much concur that there is no clinical indication to repeat an MRI scan. It would not give any information to help diagnosis or treatment. It gives information about the structure of the brain, but not about the function of the brain. What gives information about the function of the brain is the clinical assessment of each child. Dr McCullagh said in her oral evidence that she did not believe that repeat MRI scans would add any more information. She said that such scans would require a general anaesthetic upon the child concerned in order to keep him entirely still for twenty minutes, and that there are risks inherent in the general anaesthetic, and inherent also in the child being placed anaesthetised in the scanner. She said that she would not routinely re-request investigations that she did not think were appropriate. The existing MRI scans have already been reported upon by experts in two separate hospitals. Dr McCullagh stressed that the existing MRI scans show a loss of tissue in the brains of each boy, which tells the doctors that there has been atrophy.

- 13 Today Dr Playfor, who has attended again, gave further oral evidence in the light of various points made by the father during the course of his own oral evidence this morning. The father showed me and Dr Playfor and others in the

court room a short video clip on his mobile phone of one of the children whilst the father was talking to him in a most tender and soothing way. It is right to say that on that clip there are visible movements of the boy's head, but Dr Playfor said that those are typical movements that that boy does produce with roving head movements. Dr Playfor has never seen any purposeful movements by either child. He repeated that both boys display abnormalities of tone and movements in their limbs and head. They display dystonia and jerking spasms. The father said that he had observed tears in the eyes of one or both boys, and suggested that this shows that they are crying and thereby displaying emotion. Dr Playfor doubts that. He said that crying is a high order function, which requires a complex process of receiving neurological information and processing it in the brain and then the physiological response of crying. The production of tears or lachrymation can be short circuited by muscles around the tear ducts, and it is much more likely that it is that process, rather than crying as an emotional response, that is being observed in these boys. He said that their muscles are not being controlled centrally by the brain. He said that they can react to pain and discomfort, but because of the degeneration of their brains they cannot process an emotional response to, for example, their parents' touch or voice. He pointed out that a normal child would be relaxed by a soothing experience such as a gentle touch or the feel of a parent, but in these children that generates muscle spasm.

14 At the very end of the case Ms Cavanagh summarised the position of the medical evidence in the following short sentences to which Dr Playfor had expressly indicated his agreement and approval. Ms Cavanagh said:

“The children are, in the opinion of the clinicians, cognitively unable to experience pleasure from comforting stimuli. However there is ample evidence that they are able to, and that they do, experience pain and discomfort.”

15 In the light of all that medical evidence, Ms Cavanagh presented a document summarising the benefits to the boys, on the one hand, of maintaining artificial ventilation and life support, and the disadvantages on the other hand of doing so. Her disadvantages column was further subdivided into disadvantages stemming from the underlying disease or disorder, and disadvantages stemming from the treatment, reflecting a point and distinction that Dr Playfor had made in his oral evidence, as I have already mentioned. With the agreement of Ms Cavanagh, I now reproduce that document:

OPTION A: STATUS QUO

BENEFITS	DISADVANTAGES
This course most closely respects the children’s parents’ wishes and beliefs.	The ventilation is intervening in the process of dying to artificially keep A and H alive this is not going to prevent their death occurring in short course.
Whilst the clinicians consider the condition to incurable this leaves	The children will continue to suffer discomfort from the interventions including life sustaining efforts on multiple

open the possibility, howsoever remote, that the children may improve and later survive without ventilation. This is their parents' hope but in the opinion of all treating doctors that is unrealistic and will not happen.	occasions a day, all of which serve no purpose in improving their health treating their underlying condition.
This respects the sanctity of life. The children may live for a number of years if all measures are taken.	If either boy goes into cardiac arrest no doctor on the PICU at RMCH is willing to undertake cardiac resuscitation as to do so is unethical in their clinical opinion.
The parents report that the children respond by a smile and turn their heads and try to avoid tickling by parents. Whilst this has not been observed clinically, even if accurate, it does not suggest that he is comforted by their presence or that they gain any benefit life. In the opinion of the doctors their brains are so atrophied that they are cognitively unable to experience pleasure from comforting stimuli.	If the children's hearts are restarted after cardiac arrest the children are put through the suffering of the initial deterioration to arrest, the resuscitation and the prospect of further suffering when it occurs again, all to no clinical purpose.
	The children's rights to have a dignified life, for as long as it remains, and death, when it comes, are not respected by this course.
	Fails to respect the children's right to physical and psychological integrity.
	The option surrenders the children to an unknown period of suffering which has the potential to be prolonged. The burdens for the children are best understood as the burdens of their underlying disease process and the burdens of the treatment.

	UNDERLYING DISEASE	TREATMENT
	<p><u>Current Condition</u></p> <p>The twins are suffering from increased muscular spasms,</p>	Respiratory interventions – the presence of an artificial airway is likely to be

	increased dystonia and recent onset of seizure activity.	unpleasant.
	The twins demonstrate increased tone (i.e. they stiffen when handled) this is probably uncomfortable. They are handled for routine matters such as nappy changes, bathing and dressing.	Suctioning is uncomfortable (clearing secretions); this is usually required when they desaturate i.e. described by children who have had this as like a painful burning sensation.
	Physiological instability: The twins have profound desaturations regularly- usually multiple times a day. These are uncomfortable; a child may experience air hunger, a sense of impending doom, and feel scared.	Physiotherapy for clearing their chests is uncomfortable for the boys they desaturate and have to be pre oxygenated in order to try and lessen the impact of the interventions.
	There is no evidence that the children have positively interacted with the world since admission to the PICU. All clinical reports of their responses to interventions (medical and non-medical) are negative.	In order to monitor the twins physiologically they have to be attached to monitors; both boys have developed a sensitivity to the tapes holding the cardiac monitors in place (this presented as an angry rash on the front of their respective chests).
	<u>Potential</u> The children currently have the ability to display discomfort which will deteriorate. Thereafter they may be unable to show signs of pain or discomfort i.e.	Feeding tubes need to be changed every 28 days or whenever they become blocked or dislodged the children have to be restrained by swaddling to do so safely; they have increased dystonia

	these signs alert clinical staff to the fact that they are suffering. This is not necessarily linked with a deterioration in their ability to feel those sensations.	and abnormal movements at these times (albeit that they do not make purposeful movements towards the tubes).
	Further respiratory deterioration- repeated chest infections, these may lead to systemic infection (sepsis), increased frequency/severity of desaturations	Blood gases are taken on alternative days and more often if their chest is worsening. This involved blood being taken. Both boys demonstrate pain and discomfort.
	Patients on long term ventilation often developed osteopenia through bone re-absorption. This may result in pathological fractures through normal handling. Also they are at risk of developing kidney stones through the bone reabsorption.	Blood is taken to monitor for electrolyte disturbances/markers of infection this involves venepuncture.
	As the children grow physically bigger, a scoliosis may develop, with associated impact on their cardiorespiratory functions, and their contractures will worsen.	Due to the increasing frequency of chest infections the twins are likely to require more IV access in order to have IV antibiotics or fluids this will require frequent venepunctures or painful procedures with anaesthetics to site more stable lines.
	The children's cardiac function is likely to deteriorate as is the pulmonary function. This is	The tracheal tubes require re-taping regularly. The twins both have to be restrained by swaddling. They grimace and

	likely to make them more vulnerable to infection and cardiac and respiratory arrest.	demonstrate other signs of pain such as increased spasms.
	Tone and dystonia are likely to worsen as it has relentlessly to date despite increase in medication.	Increased spasms and tone are themselves uncomfortable this occurs when handled for numerous medical interventions set out and is additional to the pain of the intervention.

The position of the guardian

16 The children's guardian has visited the children in hospital, albeit relatively briefly. She made a decision, with which I agree, not to seek to obtain further independent expert evidence in view of the existence already in this case of the independent second opinion of Dr McCullagh. The considered position of the guardian, which she reaffirmed by her brief oral evidence this afternoon at the close of all the other oral evidence, is to support the making of the declarations that the hospital seek. Ms Melanie Carew, who appears on behalf of the guardian, prepared a similar, though shorter, table of benefits and burdens to which I attach weight - coming as it does from the guardian - but I do not further lengthen this judgment by reproducing. Essentially, there is overlap in the considered opinion and approach both of the doctors and of the guardian.

The position of the parents

17 As I have said, the father has chosen to act in person throughout, although I understand that a very well-known firm of solicitors had offered and was available to act on his behalf. So, during the two days of this hearing (last Tuesday and again today), I have engaged very considerably with the father, both in his role as a self-representing party and also in his role as a witness when he gave his very measured evidence upon the Koran today. Both parents are of the Islamic faith and the father appropriately stresses to me the contents of a document, the original of which is in Arabic script but of which a translation has been supplied to me. That translation reads, so far as material, as follows:

“The second resolution on death report and removal of life support instruments from human body

The Islamic Fiqh Council of the Muslim World League during its tenth session held between...17-21 October 1987 looked into the issue of report on death based on clear medical indications, and into the permissibility of removing the life support instruments from the patient who is under intensive care.

After discussion and deliberation on the issue from all its aspects and dimensions, the Council adopted the following resolution:

The life support instruments which have been installed upon the body of patient can be removed from him, when all the functions of his brain have stopped working finally, and a panel of three medical specialists and experts decides that this situation of the brain is irreversible, though the heart and breathing are still continuing due to the life support instruments. However, he will not be declared legally dead unless heart and breathing fully stop working after removal of the life support instruments.”

I do not think it is suggested in this case that either boy has reached the point where it could be said that “the functions of his brain have stopped working finally” within the sense of that document.

- 18 During the course of his oral evidence, the father testified and made a number of points. He said that when he or the mother tickle the boys they start moving to avoid it. He said that they start smiling. It was in later answer to that evidence that Dr Playfor was to say, as I have already quoted, that these movements that the father observes in the children are not in truth indicative of pleasure. They are in fact random roving movements by the child concerned. The father then made the very important point that he believes that the Merciful God may one day enable medical science to advance so as to find a cure, and so he pleaded that the boys should be kept alive so as to be able to benefit from that cure. I regret to say that the evidence of all the doctors leaves

me satisfied beyond any doubt that there is in truth no prospect of a cure for either of these boys ever. The father then made the point that a number of the disadvantages highlighted by Dr Playfor and included within Ms Cavanagh's list are, as he put it, "for the future". That is in fact correct. For instance, there is a prediction that, if the children remain alive, scoliosis may, or will, develop as they grow physically. There is a prediction that they are at risk of developing osteopenia and kidney stones. These are predicted complications, not current complications. But the tenor of the evidence of all the doctors is that already these children are currently suffering so many complications, and suffering pain and discomfort from current treatment, as to make prolongation of the treatment not only futile but unjustifiable. The father made the point that some of the pain and discomfort, for instance from the insertion of needles and cannulae, may be reduced, if not eliminated, by applying forms of local anaesthesia.

- 19 The father stressed again how offensive it is to the Muslim beliefs of himself and his wife that life support should be withdrawn before the brain of the respective child "has stopped working finally" in accordance with the resolution of the Islamic Fiqh Council. He said, most eloquently, "I have respect for the law of the United Kingdom, but, please, do not forget that withdrawal of life support goes against our beliefs." In this regard I refer to what I said at paragraph 49 of my judgment in *MB*, and repeated at paragraph 41 of my judgment in *The NHS Trust v A* [2007] EWHC 1696 (Fam):

“This case concerns a child who must himself be incapable, by reason of his age, of any religious belief. An objective balancing of his own best interests cannot be affected by whether a parent happens to adhere to one particular belief, or another, or none. I have the utmost respect for the father’s faith and belief, and for the faith of Islam which he practises and professes. But I regard it as irrelevant to the decision which I have to take and I do not take it into account at all.”

In A I was able to continue:

“In the present case all counsel, and specifically Mr Philip Havers QC on behalf of the parents, accepted and agreed with the correctness of the approach in that paragraph...”

- 20 The father also raised concerns about whether the nursing staff have always been as attentive as they should be, and urged me not to place much reliance upon the nursing report, which was attached to the report of the guardian but to which, for that reason, I make no reference. I wish to stress, however, that none of the nurses have had any opportunity to comment upon some of the oral evidence of the father today; and I stress very clearly indeed that I neither express, nor imply, the slightest criticism myself of the dedication or expertise of the nurses. The father also made the point that withdrawal of life support and the consequent deaths of the children would not affect just him and his wife and their elder surviving son, but also the whole family, most of whom remain in Iraq. I completely understand and deeply sympathise with that point.

However, as is clear from the propositions of law quoted above, my decision must be governed solely by the best interests of each of these children themselves. I cannot ultimately be influenced by the obvious impact upon, or sympathy for, the families.

Outcome

21 I have already announced before commencing this *ex tempore* judgment what my decision is, namely to make declarations in the terms sought. I did so, because I felt it would be unkind to the father, who attends alone and unsupported, save by the independent interpreter, to have to sit through a long judgment in a state of great anxiety and uncertainty as to outcome. In my judgment in the case of *MB*, I stressed very strongly in the “Concluding comments” at paragraphs 106 to 109 how very fact specific a decision of this kind always is. Every child is unique, and the court needs to focus totally upon the child or children with whom it is currently concerned. It is neither helpful nor appropriate in cases of this kind for courts to engage upon the legal technique of “distinguishing” so frequently adopted by lawyers and judges in most other legal contexts. That said, I appreciate that there are obvious points of similarity between the situation with which I was concerned in the case of *MB*, and the situation with which I am concerned in this case. A reader of this judgment, who is familiar also with that judgment and decision, may reasonably wonder why the same judge declined to authorise the withdrawal of

artificial ventilation in that case when, as I have indicated, I propose to do so in this case. There is, however, a very significant difference in the condition and circumstances of the child or children in these respective cases. That difference turns upon cognition.

22 In paragraph 63 of my judgment in that case I said of the child in that case that:

“It is possible that he has some degree of brain damage or impaired cognition, but that is uncertain and is not a normal feature of SMA. Although Dr Hughes said, correctly, that there is no objective evidence to support that his cognition is normal but none to support that it is not normal, she agreed that one must make the assumption that it is normal. In my view it would be totally unacceptable (and false legal reasoning) to proceed on any other basis. I accordingly must proceed and do proceed on the assumption that M has normal, age appropriate cognition and power of thought; and normal, age appropriate capacity for moods and emotions, and the capacity to feel pleasure from the stimuli he may receive...”

At paragraph 68 of my judgment in that case, I said:

“But whether [the parents] do or do not detect genuine reactions, it does not affect my view that neither I, nor anyone, are justified in assuming

that he derives less pleasure now simply because he has lost the capacity to react.”

At paragraph 101, when assessing the benefits of maintaining life support, I said:

“Within those benefits, and central to them, is my view that on the available evidence I must proceed on the basis that M has age appropriate cognition, and does continue to have a relationship of value to him with his family, and does continue to gain other pleasures from touch, sight and sound...”

At paragraph 106, I referred to the very fact specific circumstances of the child in that case and said:

“These circumstances include, critically, the facts that he already has been and is on ventilation and has already survived to the age of 18 months; is assumed not to be brain damaged; is in a close relationship with a family...; and does already have an accumulation of experiences and the cognition to gain pleasure from them.”

23 Tragically, I deeply regret that the situation in the present case is in fact diametrically the reverse of the situation in that case. In that case, the

assumption had to be that the brain of the child concerned was undamaged and was functioning normally, since brain damage is not a normal feature of the condition he suffered of spinal muscular atrophy (“SMA”). The disease or disorder that that child suffered was a complete inability actually to move any of his voluntary muscles. Therefore he was unable to breathe naturally, and unable in any way whatsoever to communicate emotion. But there was no evidence of any damage to any of his senses, and no evidence that he did not process stimuli in a normal way within his brain, so as to experience within his brain all the normal pleasures and emotions of an eighteen month old baby.

- 24 The circumstances of these two boys is the reverse. Their disorder does not relate to their muscles. It relates fundamentally to their brains. Their muscles, to a degree, do function. The problem for these boys is the atrophy and degeneration of their brains so that, as Dr Playfor said this afternoon in a passage I have already quoted, “because of the degeneration of their brains they cannot process an emotional response...” So also, in that short proposition by Ms Cavanagh that I have already quoted, “The children are, in the opinion of the clinicians, cognitively unable to experience pleasure from comforting stimuli.” So, although there may be much superficial similarity between the circumstances of these two boys and that of MB in that case, on proper analysis their situations are completely different.

25 In this case, the medical evidence satisfies me that these children already have severely damaged, or atrophied and malfunctioning brains. I could not go so far as to say, in the language of the Islamic Fiqh Council's second resolution, that their brains "have stopped working finally", but they are not functioning cognitively at all. These boys are merely artificially surviving. Their situation is unquestionably irreversible, and can only deteriorate progressively further. I give the fullest possible weight to the strong presumption for the prolongation of life to which I referred in paragraph (vii) of the ten propositions. But it seems to me that artificially to prolong their lives in this particular case lacks any purpose, confers no benefit at all apart from the fact of physical survival, and involves perpetuating the infliction of pain and discomfort for no gain or purpose. It is not in the best interests of either boy that the process be artificially prolonged, and it is in their best interests that nature should now be permitted to take its inevitable course. That is the tragic genetic destiny of each of these boys.

26 I will accordingly grant declarations in relation to each child separately and specifically, but in the same identical terms, namely:

“

- (a) It is lawful and in the best interests of [the respective child] for the clinicians of the Royal Manchester Children's Hospital to withdraw mechanical ventilation from him after due and

careful consideration with his parents as to implementation of the process.

(b) In the event of a serious deterioration in [the respective child's] medical condition, it is lawful and in his best interests for the following medical treatment to be withheld:

(i) Bag and mask ventilation, save to the extent that it is considered to be clinically appropriate in any given situation;

(ii) Endotracheal intubation;

(iii) Invasive or non-invasive ventilation.

(c) In the event of a serious deterioration in [the respective child's] medical condition which leads to a cardiac arrest, it is lawful and in his best interests not to administer cardiac massage and resuscitation drugs including Inotropes.

(d) In the event of a serious infection, including pneumonia, it is lawful and in [the respective child's] best interests not to undergo blood sampling or to receive intravenous antibiotics unless it is considered that such treatment would help to make him more comfortable and/or distress and pain free.

(e) It is lawful and in his best interests for [the respective child's] treating clinicians to provide him with palliative care only.

Provided always that the measures and treatments adopted are the most compatible with maintaining his dignity.”

Note added by the judge when approving this transcript: I have been informed that, after discussion with both parents and an Imam, the ventilation was withdrawn from both boys, at the hospital, about five days after this judgment. They died and have been buried. May they rest in peace.