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IN THE HIGH COURT OF JUSTICE IN NORTHERN IRELAND

FAMILY DIVISION

OFFICE OF CARE AND PROTECTION

IN THE MATTER OF M

BETWEEN:

A HEALTH AND SOCIAL CARE TRUST

Plaintiff;

and

M and A and L

Defendants.

O'HARA J

[1] Nothing must be reported in this case which would serve to identify the child who is the subject of the proceedings or of any of the parties named therein.

[2] The issue in this application is whether a 5 month old baby, M, should be removed from a ventilator and made the subject of palliative care only. The majority of the medical evidence is that if this is done he will not be capable of breathing for more than a short time, perhaps a day or so at most, due to catastrophic and irreversible brain injuries suffered on 7 March 2014.

[3] A trust has applied for a declaration that this course of treatment would be lawful in the circumstances of this case. The Trust was represented by Mr A Montgomery. For the father L, Ms McGrenera QC appeared with Ms A O'Grady. The child M was represented by Ms Gibson QC, instructed by the Official Solicitor. The Official Solicitor also represented the mother A, with Mr Colton QC and Mr S Doran appearing for her. Sadly A is currently a patient and is not competent. I am grateful to all counsel and representatives for their helpful and concise

submissions.

The Medical and Family Evidence

[4] M was born in October 2013 in the homeland of his married parents. He is their second child. By Christmas they had returned to Northern Ireland where they have lived for some years. M was a healthy baby until 7 March 2014 when an incident occurred which led to him being taken to hospital. It was immediately apparent that the situation was critical. His heart had stopped. As a result of prolonged resuscitation the heart started again but severe damage had been caused, especially to his brain. M has remained in paediatric intensive care since that time, approximately 4 weeks ago. He has remained intubated because the doctors believe that he cannot survive otherwise.

[5] Four consultants gave evidence in support of the Trust's application. They were Dr A who is a consultant paediatric neurologist, Dr B who is a consultant in paediatric anaesthesia and paediatric intensive care, Professor C who is a consultant paediatrician in paediatric respiratory and general paediatric medicine and Dr D who is a consultant intensivist in paediatric intensive care. Their evidence, in the written reports which were before the court supplemented by oral testimony, was to the following effect:

(i) M has suffered overwhelming and irreversible brain damage with no higher brain function and very limited lower brain function which is exhibited mainly in rudimentary abnormal breathing.

(ii) It is likely (but not certain) that as a result of the loss of higher functioning he is not in pain.

(iii) His pupils do not respond to light nor do his cornea react when touched.

(iv) He has no gag or cough reflex.

(v) Successive scans have shown no improvement.

(vi) There has been significant damage to his bowel as a result of hypoxia on 7 March. This has led to his abdomen being distended and to concerns, which have abated for the present, about perforation of the bowel.

(vii) While there was some liver damage as a result of the hypoxia, that has improved with oxygen and time.

(viii) M has been kept alive by a ventilator because it is believed that he could not breathe unaided for more than a short time.

(ix) This is an untenable long-term solution for a baby who in all likelihood is now blind, deaf, severely mentally handicapped and severely physically handicapped.

(x) Notwithstanding the nursing and physiotherapy care and attention which he is receiving to stretch and massage his limbs, there are already signs of tightening and clenching which come when the limbs are not used.

(xi) M can never recover to any form of living which does not involve continual ventilation. He would not be able to interact with anyone and would have no recognisable quality of life.

(xii) The longer he stays on this form of life support the more likely it is that he would develop pneumonia and other infections which would aggravate an already dreadful situation.

(xiii) It is not appropriate to carry out a tracheostomy to facilitate ventilation. While this would help with nursing care (eg to remove secretions), it would require surgery which would be low risk but which would still involve another invasion of or assault on his body.

[6] The consultants referred to guidelines issued in January 2014 by the Royal College of Paediatrics and Child Health. They are entitled "Making decisions to limit treatment in life-limited and life-threatening conditions in children: A framework for practice." Section 3.1.3 of the guidelines refers to "Situations in which it is appropriate to limit treatment" and states:

> "The underlying ethical justification from all decisions to withhold or withdraw LST [life sustaining treatments] is that such treatment is not in the child's best interests. There are three sets of circumstances where it may be appropriate to consider limitation of treatment."

[7] In so far as it is relevant to this case the text continues as follows at 3.1.3.1:

> "Limited quantity of life
>
> If treatment is unable or unlikely to prolong life significantly, it may not be in the child's best interest to provide it. …
>
> C. Inevitable demise
>
> In some situations death is not imminent (within minutes or hours) but will occur within a matter of days or weeks. It may be possible to extend life by treatment but this may provide little or no overall benefit for the child. In this case, a shift in focus of care from life prolongation per se to palliation is appropriate."

[8] On behalf of the father L the views were sought of a consultant from outside Northern

Ireland who had not previously been involved in the care of M. A report was provided by Professor Y who is a consultant paediatric neurosurgeon in a hospital in England. His conclusion was even more definite than that of the consultants in Northern Ireland. It was as follows:

> "I wish to itemise my conclusion as follows –
>
> 1. M suffered a severe and complete hypoxic injury on 07.03.14 from which he has shown no signs of recovery.
>
> 2. M now has fixed and dilated pupils, which in neurological/neurosurgical terms is a sign the patient is deceased, meaning there is also no indication for further treatment."

I believe that in his second point the professor is not asserting that M is dead, only that having fixed and dilated pupils is one of the signs of death. Nevertheless his report was such that while he was available to give evidence it was agreed that he need not be called.

[8] In their entirely understandable desperation to find somebody and something more hopeful, the father and extended family turned to their homeland where they made contact with a Professor Z. According to his curriculum vitae he is an army trained surgeon who has gone on to specialise in rehabilitation of patients, with adults and children who have suffered what others regard as injury from which there could be no recovery. These patients have included many who were in comas and who had suffered severe traumatic injuries. Professor Z is not a neurologist, a paediatrician or an anaesthetist. He is described in the father's affidavit as "a controversial figure".

[9] The Professor was sent video-clips of M in intensive care, with his eyes being opened and with his chest being pinched in order to see if and how he would react. His interpretation of these pieces of film is set out in his translated report as follows:

> "1. A child M is alive, his body is appropriate to his age, his reactivity is retained, the skin complexion normal. He moves his tongue, blue eyes, the pupils are round, equal, of the average wide, they seem to react to light, closing of the eyelids is efficient.
>
> 2. M is clearly arguing with the respirator which proves the attempts of his own breath as confirmed by the doctors in charge.
>
> 3. Changes during MR and CT tests, similar to those described, however, do not provide convinced evidences of changes which do not allow for further independent life."

[10] On that basis the opinion of Professor Z as to the way forward was that:

> "M has a chance to continue his life as comfortable if they are met the following conditions:
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> - In a short time there must be connected the tracheostomy tube.
>
> - The child needs a high protein and high calorie intra-gastric feeding, adjusted over his age.
>
> - In the nearest 24-30 hours there should be used neuro-stimulations restoring spontaneous breathing.
>
> As for the recovery of efficient aspiration, there should be gradually increased the time breathing without assistance,
>
> - There should be provided immediately an all day neuro-stimulation of sensory organs and the whole body of the child until the recovery of fitness. Stimuli is to be exercised by the child's family according to my standards described in the printed monograph. The family should immediately report to me in order to be instructed on respiratory stimulation, sensory organs and the whole body.
>
> - After taking control over the clinical state there will be possible a further rehabilitation under my supervision."

[11] The family provided a DVD which showed Professor Z demonstrating on M's great-uncle how neuro-stimulation should be performed. The great-uncle then came to Belfast and followed the Professor's lessons by stimulating M. In an unsworn statement which I accepted in evidence, the great-uncle said that he saw M respond, for instance the pupil of his right eye moved twice. He said this had been reported to hospital staff.

[12] The reaction of the local consultants to Professor Z's report and to the DVD showing neuro-stimulation was stark and to some extent angry. They said that while they agreed with his second finding in the sense that M was struggling to breathe, his first and third findings were simply wrong. Their opinion is that Professor Z has misunderstood and misinterpreted the video clips which he was sent. M is not moving his tongue, his eyes do not react to light and the closing of the eyelids is an entirely passive act rather than a sign of life. They also said that the scans referred to at point 3 by the Professor show conclusively irreversible damage which rules out further independent life.

[13] Their response to the neuro-stimulation as demonstrated in the DVD was uniformly negative. It appeared to them to be no more than massaging of the face and head, something

which cannot possibly reverse brain damage. Dr B's response to this notion was that it was "utter nonsense" which only gave false hope to L.

[14] Professor Z's evidence was that M could recover to the extent that he could leave hospital, go to nursery and then on to school as a result of neuro-stimulation and further treatments which he did not have time to demonstrate on the DVD. He accepted that his treatment was unique and that it was not copied widely because it involves hard work and because it gives rise to a conflict of interest for doctors (though he then refused to develop the second point and withdrew it).

[15] L gave oral evidence in which he expanded in the most moving terms on his affidavit. His distress and desperation are almost unimaginable. Until 4 weeks ago he and his wife had two children, both healthy and well, as they made their lives and their home in Northern Ireland. Suddenly he has found that his baby has been catastrophically injured with doctors telling him that there is no hope of recovery. He and his wife are both religious – they believe in the sanctity of life and in the obligation to do everything possible to preserve and to take every last step to help M. His request was that I should reject the Trust's application or at least adjourn it for two weeks to see if the neuro-stimulation recommended by Professor Z worked. In his view there was nothing to lose by trying this since M is said to be in no pain.

[16] A, the mother, was unable to give evidence. On her behalf Mr Colton QC relayed her necessarily limited views which are that ventilation should continue but without M being resuscitated in the event that resuscitation becomes necessary. She was primarily concerned about M being in pain – so long as he is believed not to be in pain, she would like his life to continue.

[17] For M, Ms Gibson QC did not support the course recommended by Professor Z and submitted that the prolongation of M's life by ventilation was not in his interests in light of the uncontradicted neurological evidence. Even on the assumption that M is not in pain, he has no perception of life and his life lacks any dignity or hope.

The law

[18] The parties were agreed on the legal principles which are to be applied in this case. The role of the court is to protect people who cannot act on their own behalf. Obviously M is one such person because he is a baby but also because of the extensive brain damage which he has suffered. I therefore have jurisdiction to consider and either accept or reject the application made by the Trust.

[19] Since it is apparent that M does not have legal capacity (the ability) to make decisions on his own behalf, the question for the court to decide is what is in his best interests. This issue was addressed by the House of Lords in Airedale NHS Trust v Bland (1993) AC 789. The case involved a 21 year old man who had been in a persistent vegetative state for 3½ years after suffering a severe crushed chest injury which caused catastrophic and irreversible damage to the higher functions of the brain. In his judgment in the House of Lords, Lord Goff

said this:

> "… The question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuation of this form of medical treatment or care.
>
> The correct formulation of the question is of particular importance in a case such as the present, where the patient is totally unconscious and where there is no hope whatsoever of any amelioration of his condition. In circumstances such as these, it may be difficult to say that it is in his best interests that the treatment should be ended. But, if the question is asked, as in my opinion it should be, whether it is in his best interests that treatment which has the effect of artificially prolonging his life should be continued, that question can sensibly be answered to the effect that it is not in his best interests to do so."

[20] Lord Goff then continued in the following terms:

> "As Sir Thomas Bingham MR pointed out in the present case, medical treatment or care may be provided for a number of different purposes. It may be provided, for example, as an aid to diagnosis, for the physical or mental injury or illness, to alleviate pain or distress, or to make the patient's condition more tolerable. Such purposes may include prolonging the patient's life for example to enable him to survive during diagnosis and treatment. But for my part I cannot see that medical treatment is appropriate or requisite simply to prolong a patient's life when such treatment has no therapeutic purpose of any kind, as where it is futile because the patient is unconscious and there is no prospect of any improvement in his condition. It is reasonable also that account should be taken of the invasiveness of the treatment and of the indignity to which, as the present case shows, a person has to be subjected if his life is prolonged by artificial means, which must cause considerable distress to his family – a distress which reflects not only their own feelings but their perception of the situation of their relative who is being kept alive. But in the end, in a case such as the present, it is the futility of the treatment which justifies its termination. I do not consider that, in circumstances such as these a doctor is required to initiate or to continue life prolonging treatment or care in the best interest of his patient."

[21] The reasoning of Lord Goff and of the other Law Lords extends far beyond the specific

circumstances of the Bland case. Since then there have been many decisions in which different judges have approached the question of what is relevant in deciding what a patient's best interests are in any circumstances. The various formulations are strikingly similar, whether they are broken down into six, ten or more points. For present purposes I will adopt the approach set out by Lord Justice Wall in the Court of Appeal in England and Wales in Wyatt v Portsmouth NHS Trust (2006) 1 FLR 554 at paragraph 87:

> "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 action which will prolong life, but that presumption is not irrebutable (Re J). The term 'best interests' encompasses medical, emotional and all other welfare issues (Re A). 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)."

[22] Lord Justice Wall continued with the following warning:

> "Inevitably, whilst cases involving the treatment of children will fall into recognised categories, no two cases are the same, and the individual cases will, inevitably, be highly fact specific. In this context, any criteria which seek to circumscribe the best interests tests are, we think, to be avoided. As Thorpe LJ said in Re S:
>
> > 'It would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination'."

[23] It is important to emphasise what this application does **not** involve. It is not an application by the Trust to take a positive step to end the baby's life e.g. by injecting him with a drug. Rather the Trust seeks a declaration that it is lawful to withhold treatment (ventilation) which is prolonging a life artificially when that life would in all likelihood come to a natural end. The doctors and nurses who saved the life of M by resuscitating him four weeks ago and who have cared for him ever since, in a way which the parents have generously acknowledged and expressed their thanks for, now believe that they can do nothing more for him. Moreover they believe that in all the prevailing circumstances it is ethically and morally questionable to continue to ventilate M and thereby keep him alive.

[24] The views and the wishes of the parents are relevant to the decision as to what is in M's

best interests but they do not determine that question. L's views are obviously important and relevant. I listened to them as they were powerfully and movingly expressed in his evidence. I also record specifically that the wishes of A, as the baby's mother, are relevant notwithstanding her current position. The views of both parents are to be taken into account.

[25] While it is clear that no two cases in this area are the same, Ms McGrenera properly drew my attention in her submission on behalf of L to a strikingly similar case to the present one, NHS Trust v Baby X (2013) 1 FLR 225. A one year old baby had suffered a catastrophic brain injury in an accident at home. This resulted in chronic, profound and irreversible brain damage. He remained unconscious with no spontaneous purposeful movement. His inability to breathe unaided meant he was permanently ventilated and he was fed by a nasal gastric tube. The care team at the hospital came to the conclusion that it was no longer in the baby's interests to remain on artificial ventilation as no improvement was expected and treatment was now futile. They proposed the withdrawal of life sustaining treatment in favour of palliative care which would result in the baby's death within hours if not minutes. The parents opposed that view on the grounds that the baby should be given every chance to improve, they believed that signs of improvement were discernible and their faith prevented them from giving consent to a course that would lead to his death. The expert evidence was essentially in agreement that it was highly improbable that X would make any discernible improvement.

[26] Hedley J gave judgment, granting a declaration that it was lawful to withdraw the life sustaining treatment. He stated:

> "The essence of the reasoning which supports this conclusion is as follows. First, I recognise the desire to preserve life as the proper starting point to which I add that X is very probably unaware of any burden in his continued existence. Against that, secondly, I have said both his unconsciousness or unawareness of self, others or surroundings and the evidence that any discernible improvement is an unrealistic aspiration. Thirdly, I have acknowledged his ability to continue for some time yet on ventilation but have balanced that with the risk of infection or other deterioration and the desire to avoid death in isolation from human contact. Fourthly, having accepted the treatment served no purpose in terms of improvement and has no chance of affecting it, I have taken into account its persistent, intensive and evasive nature. Fifthly, I have noted the treating consultant's view that X shows no desire to live or capacity to struggle to survive which are the conventional marks of a sick child; although I think that that observation as such is correct, I would not want that to have significant let alone decisive weight in this balance."

[27] For completeness it is worth adding that it appears that the approach taken in England and Wales is also followed in the Republic of Ireland. I was helpfully referred by counsel for

L to an article in the Medico-Legal Journal of Ireland (2011) at page 83 which analysed the decision of the Supreme Court of Ireland in Re A Ward of Court (1996) 2 I.R. 79 in which the best interests of the ward (a woman of 45) were the focus of the decision.

Discussion and conclusion

[28] Since Professor Z holds the only contrary medical opinion I will deal with his report and recommendations first. I believe that he has misinterpreted or over-interpreted the medical evidence at the first and third points in his report. He is of course at the disadvantage of having to rely substantially on the DVD of M whereas the four local consultants have seen and examined M repeatedly in recent days and weeks. After Professor Z gave his evidence by phone link on the first day of hearing, Dr D took the trouble to re-examine M before she gave her evidence the next morning to see if she could find any sign of his pupils reacting to light. She confirmed in her evidence that she had found none. I must prefer the evidence of the local consultants about the true state of the health of M to that of the professor.

[29] That finding alone undermines the recommendations made by the professor which must be based on his clinical findings. In any event, only one of his three recommendations is of significance. His opinion that M should have a tracheostomy is not significant because that would only provide an alternative method of ventilation to the current method. Similarly his recommendation about how M should be fed is of little relevance – the fact is that M relies entirely on being fed artificially and the precise method matters not in terms of stimulating recovery. This leaves the recommendation and opinion that M can be saved by neurostimulation. I was struck by the disbelief shown by the Trust witnesses when they saw this being demonstrated by Professor Z on a DVD. What they saw was no more than gentle massaging of the face and head, leading on to massaging of other limbs. The consultants seemed bemused by the proposition that this could in any way start to reverse brain damage – so am I. I am afraid that there is no evidence to support Professor Z's contentions. I dismiss his contribution to the case as being of no value. To make matters worse, his contribution has given a distressed, grieving family false hope where there really is none.

[30] As suggested by the Court of Appeal in Wyatt and other cases, I invited the parties to draw up lists setting out the benefits and burdens to M of continuing ventilation. There is inevitably a significant overlap between the lists which were put forward. Excluding Professor Z's proposals, it is contended that the benefits of continuing ventilation are that M is alive, that he is in a stable condition, that time is available to him, that he can breathe unaided to a limited degree, that he is not in pain and that he has the devotion of a loving family. As against that it is suggested that he is irreversibly brain damaged, devastatingly handicapped, at risk of physical deterioration which is already evident, without hope of recovery or even improvement and utterly dependent.

[31] In cross-examination Dr D was asked if she understood L's determination to do all that he could not to lose his baby son. Her simple reply was that in many ways L had lost M already.

[32] I agree with Dr D. L and A and the whole family are distraught by recent events, both by what happened, how it happened and how it has left M. Their efforts to find any possible way to salvage some future for him are natural, inevitable and entirely understandable. The inescapable problem however is that on the evidence before me there is no conceivable outcome other than "inevitable demise" the term used by the Royal College in its guidelines. (I emphasise that the fact that this or any other case fits within the guidelines of the Royal College does not mean that the Trust's declaration should be granted since there are certainly circumstances which can lead to a refusal to such a course of action or at least a delay before it is followed.)

[33] I have considered as carefully as I can the issues in this case by reference to the approach set out in the Wyatt decision. The starting point must always be that life should be preserved and continued other than in exceptional circumstances. Added to that side of the balance are the parents' wishes and the support and commitment of the extended family. Regrettably the other side of the scales weighs much heavier. The extent of the damage to M is such that he has and will have no quality of life, he will always be dependent, his physical condition will deteriorate and he will be prone to complications which will require further treatments. In short he has no meaningful life and no dignity nor will he have in the future. The prolongation of his life by ventilation can achieve nothing other than prolongation of life for its own sake. In the circumstances of this case I do not believe that is enough.

[34] The fact that this baby will be able to breathe unaided for an indefinite and unknown short time might be more significant if that time was likely to increase as his body recovered from the events of 7 March. However the medical opinions, which I accept, are that it will not. No one can be sure whether he will survive for a few hours or for a day or more but the expectation is that any survival will be very short lived. (If that turns out not to be the case and M shows signs of being able to survive without intubation he will be supported and the new situation will be assessed to see what should be done next).

[35] In all the circumstances I am driven to conclude that I should make the declarations sought by the Trust. I therefore order and declare that it is in the best interests of M, notwithstanding the position of his parents, that the medical consultants responsible for his care shall be permitted to withdraw intensive support by means of extubating him in a planned manner from a ventilator with a view to not reintubating him if he does not tolerate this. I also order and declare that it is in his best interests that he be provided only with symptomatic support, such treatment to be at the discretion of the medical practitioners responsible for his care and that this support should not include active resuscitation. Finally I order and declare that all such steps as are deemed appropriate shall be taken to ensure the best possible palliative care and comfort of M.

[36] Dr D described in detail the way in which any order would be put into effect. The family will be consulted about the timing of the withdrawal of ventilation. They will be given time to assemble and they will be given the greatest degree of privacy possible in the intensive care setting. It appears that A will be included in these arrangements – I very much hope that this happens.

[37] I should not finish this judgment without acknowledging the efforts which have been made by everyone who has treated M to do all that they can for him. I also acknowledge that the family has done all it can for M, especially L his father. I hope that in time he will gain some small comfort from the fact that he did everything he could for his baby son.