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*Judgment: approved by the Court for handing down
(subject to editorial corrections)**

Court Ref: DJ 2022/40

Delivered: 03/05/2022

IN THE HIGH COURT OF JUSTICE IN NORTHERN IRELAND

FAMILY DIVISION

OFFICE OF CARE AND PROTECTION

Between:

A HEALTH AND SOCIAL CARE TRUST

Applicant;

and

RL

and

THE PARENTS OF RL

Respondents.

Ms M Connolly QC with Ms C McGrane BL (instructed by the Directorate of Legal Services) for the Health and Social Care Trust

Mr P Gillen BL (instructed by Terence McCourt Solicitors) for the second and third respondents

Ms M Rice BL (instructed by the Official Solicitor) appeared as *amicus curiae*

McFARLAND J

Introduction

[1] This is an application by the Trust seeking a declaratory order that RL should be determined as having died at 15:12 on 20 April 2022 together with consequential orders concerning withdrawal of medical intervention.

[2] This ruling has been anonymised to protect the identity of RL and his family members. I have used the cipher RL for his name. These are not his initials and they have been chosen randomly. Nothing can be published that would identify RL, without leave of the court. I have also made a preliminary ruling that the identity of the Trust, the medical staff who gave evidence and an expert witness called by the

parents of RL should also remain anonymous. I will reconsider any aspect of this reporting restrictions order should a party, or other interested person, apply to the court.

Background

[3] RL was born 21 years ago and had been living in Northern Ireland. He is a citizen of another country (which I will call "FC") and his parents continued to live in that country. On 31 March 2022 he suffered a cardiac arrest secondary to a severe allergic reaction (anaphylaxis) to a yet undetermined allergen. The ambulance service were able to attend shortly after he had contacted the 999 service. Cardiac arrest was witnessed by the ambulance staff and they applied immediate cardiopulmonary resuscitation ("CPR"). CPR continued in the Emergency Department of a hospital resulting in the return of spontaneous circulation. RL was then intubated and mechanically ventilated before transfer to the intensive care unit later that day. He has remained in that unit ever since.

[4] An initial CT scan on 31 March 2022 indicated appearances of global ischaemic injury. He failed to display any signs of neurological improvement and this was confirmed by an MRI scan on 7 April 2022. This scan showed appearance of:

- Severe global cerebral oedema secondary to global hypoxic injury;
- Effacement of cerebrospinal fluid spaces and basal cisterns;
- Marked inferior transtentorial herniation; and
- Marked cerebellar herniation through the foramen magnum.

[5] The collective view of the medical team responsible for RL was that at this stage the evidence pointed towards a cessation of his brain-stem function and as a consequence he was dead on the basis of neurological criteria. Confirmation of this diagnosis required brain-stem testing. The parents of RL at that stage were not supportive of such testing.

[6] In consultation with the parents of RL and consular officials of FC, efforts were made to facilitate the transfer of RL to a facility in FC but this proved impossible as hospitals in FC were not prepared to accept any patient whose brain-stem functioning had ceased and that required testing of this function before consideration of any transfer. Other institutions, similar to hospice institutions in this country, had indicated a potential willingness to accept RL but, to facilitate transfer, this would require surgical intervention in the form of a tracheostomy and percutaneous endoscopic gastrostomy ("PEG") to provide a means of breathing and feeding. There was a high degree of reluctance on the part of the Trust's medical team to consider such surgical interventions given the presentation of RL and an assumed diagnosis of the cessation of brain-stem function.

[7] Two intensive case consultants, Dr AB and Dr CD, then carried out a series of tests on 20 April 2022 in accordance with the standard practice based on a code of practice issued by the Academy of Medical Royal Colleges 2008 (“the 2008 Code”). These tests involved first Dr AB conducting the series of tests and being observed by Dr CD, and then Dr CD repeating the tests and being observed by Dr AB. The results of the tests were recorded. I will set out in more detail the nature and purpose of these tests. They were conducted in the presence of RL’s parents.

[8] The tests confirmed a cessation of brain-stem function. Dr AB and Dr CD were therefore both of the opinion that at the conclusion of first test by Dr AB, 15:12 on 20 April 2022, RL was dead based on neurological criteria.

[9] As a consequence of the results of the tests and the diagnosis of brain-stem death, transfer of RL to a hospital in FC could not take place. The doctors in FC accepted the results and saw no purpose in any transfer of RL as medical treatment of RL in these circumstances would be not be considered either humane or dignified and would be for no purpose.

[10] The parents of RL were understandably distraught and had sought out several institutions in FC, one being a hospice/end of life facility (“the Facility”), and the other being a clinic run by Professor EF (“the Clinic”).

[11] The Facility indicated that they would consider transfer of RL but this would require the surgical intervention referred to at [6] above again raising ethical issues for the medical team treating RL. Although RL, whose life had been diagnosed as being extinct, would suffer no pain or discomfort through the surgical procedures, with no prospect of any recovery of consciousness, it was considered that exposure to these further invasive treatments to be unethical.

[12] I will deal with Professor EF’s evidence in more detail below. He is a clinician who does not accept the concept of “brain-stem death” and runs a private clinic at which patients who are in a state of what he describes as “cerebral coma” are subject to what he describes as “neurophysiotherapy” and “neuroprotection”, and by such means he asserts that he has “awakened about 1,000 patients from cerebral coma, including patients considered to be dead.”

[13] Professor EF indicated that his Clinic would be prepared to accept RL, but he too would require the surgical interventions mentioned at [6] above.

The proceedings

[14] The Trust applied for the declaratory relief by summons dated 25 April 2022. The matter was listed for review before Dame Siobhan Keegan CJ later that day, and pursuant to further directions, including an invitation to the Official Solicitor to appear as *amicus curiae*, the matter came on for hearing before me on 26 April 2022.

[15] The hearing was a hybrid hearing under the provisions of the Coronavirus Act 2020, with counsel and two solicitors attending in court, and one solicitor attending remotely. Evidence was received from Dr AB, Dr CD and Professor EF, each giving their evidence remotely. Professor EF did not speak English and gave his evidence through the auspices of an interpreter, who also attended remotely. The parents of RL had indicated that they did not wish to attend the hearing given the level of emotional upset it was likely to cause, but through their counsel they indicated that they were content for the court to deal with the matter in their absence.

[16] At the conclusion of the hearing, I gave a short *ex tempore* ruling granting the relief sought by the Trust. I indicated that a written judgment would issue in due course and this judgment sets out my full reasons for granting the relief. I also imposed a stay of 24 hours on the operation of the relief to enable the parents of RL to consult with their legal representatives.

The legal position in relation to determination of death

[17] There is no statutory definition of death.

[18] Developments in medical science and technology have resulted in the medical profession moving away from what had been an association of death with breathing and heartbeat to a recognition that brain-stem function is now the determining factor. Lord Keith in *Airedale NHS v Bland* [1993] AC 789 at 856 stated:

“a person is not clinically dead so long as the brain stem retains its functions”

[19] In most cases it is a relatively straightforward decision for a medical practitioner to determine death by consideration of cardiorespiratory criteria with the cessation of breathing and heart function.

[20] The shift in emphasis towards lack of brain-stem function, and therefore neurological criteria, resulted in the Academy of Medical Royal Colleges first considering and then publishing its 2008 Code. This code has been accepted both within medical and legal circles as an authoritative publication providing guidance as to evidence of death. The Court of Appeal in *Re M* [2020] EWCA Civ 164 at [13] and at [91] stated that the recognised method of clinical assessment of death by neurological criteria in the United Kingdom was set out in the 2008 Code (and in a subsequent guidance in relation to children under 2 years) and that this was the test to be adopted.

[21] The 2008 Code defines death at [2] (page 11) as:

“The irreversible loss of those essential characteristics which are necessary to the existence of a living human person ... the irreversible loss of capacity for

consciousness combined with irreversible loss of capacity to breath.”

Appendix 5 explains that determination of death could be confirmed by either the irreversible cessation of brain-stem function or the irreversible cessation of cardiorespiratory function. The brain-stem is described as controlling all the essential functions that keep people alive.

[22] At [2.1] (page 11) the 2008 Code goes on to emphasise the relevance of cessation of brain-stem function for patients remaining on respiratory support. The loss of integrated biological function will inevitably lead to deterioration and organ necrosis within a short time. In addition, the 2008 Code highlights that the cessation of brain-stem function does not entail the cessation of all neurological activity in the brain. There remains a possibility of residual reflex movement of limbs through control exercised by the spinal cord.

[23] It is important to recognise that this is not a case which falls into the category of case such as *Airedale NHS* where the patient is still alive and the court is being asked to make a decision to terminate medical intervention by applying a ‘best interests’ test. This case falls into a different category of case of the Trust seeking a declaration that RL is now deceased, with consequential declarations that the Trust can cease to mechanically ventilate, intubate, administer medication and intervene when cardiac output ceases.

[24] The issue before the court is therefore a fact-finding issue.

[25] The correct approach to be taken by the High Court to such an application appears to have its genesis in a decision of Johnson J in *Re A* [1992] 3 Med LR 303 when he made such a declaration in respect of a child, holding that it was therefore not possible to exercise inherent jurisdiction that it would have over a live child, although in the circumstances the court could declare that withdrawal of ventilation would not be unlawful.

[26] Hayden J in *Re A* [2015] EWHC 443 set out a structure for dealing with cases of this type which received the approval of McFarlane P in *Re M*. Hayden J considered that the High Court exercising its inherent jurisdiction and/or acting *parens patriae* had jurisdiction over a person’s body and could make declaratory relief both as to the state of death and any consequential matters such as removal of a body from a ventilator. This general approach has been followed by Lieven J in *Re M* (at first instance) and Sir Jonathan Cohen in *North West Anglia NHS Foundation Trust v BN* [2022] EWHC 663.

[27] Francis J in *Oxford University NHS Trust v AB* [2019] EWHC 3516, although basically following the structure of Hayden J in *Re A*, expressed his reasons for the withdrawal of treatment as being in the best interests of the deceased. The Court of Appeal in *Re M* (at [49]) considered that he had fallen into error as once death had been established the concept of ‘best interests’ no longer had any legal relevance.

[28] It is of benefit to set out the conclusions of the Court of Appeal (McFarlane P, Patten and King LLJ) in *Re M* in some detail as it outlines the correct approach for consideration of the issues in this case, and in other similar cases:

“91. Firstly, as a matter of law, it is the case that brain stem death is established as the legal criteria in the United Kingdom by the House of Lord's decision in *Bland*. It is not, therefore, open to this court to contemplate a different test.

92. Secondly, as, I think, Lord Brennan accepted, it is, in reality, impossible for this court now to embark upon an assessment of whether a different test, namely that adopted in the USA, should replace the long established UK criteria represented, in modern times, by the 2008 Code and the 2015 guidance.

93. Thirdly, for the reasons given by Mr Davy, tragically the medical evidence demonstrates that this is not a case in which such difference as there is between "brain stem death" and "whole brain death" is relevant. It is not necessary to repeat the graphic descriptions of Dr G and Professor Wilkinson that have been given on the basis of the November MRI scan and the January EEG. The position is that, awfully, Midrar's body no longer has a brain that is recognisable as such.

94. Fourthly, there is no basis for contemplating that any further tests would result in a different outcome. The 2008 Code is plain that, medically, no further tests are normally required. In this case, further tests have, indeed, been undertaken and they not only confirm the DNC diagnosis but, as I have described, they take matters further by providing clarity as to the disintegration of the brain tissue.

95. Fifthly, the factual and medical evidence before the judge was more than sufficient to justify her findings. Indeed, no other conclusion was open to Lieven J on that evidence. Even if there had been room for doubt, that must surely now have been removed following Professor Wilkinson's intervention on 30 January. Given his great expertise on this particular issue and his role as an expert instructed by the parents for the purpose of considering a potential appeal, his opinion, which is 100% on all fours with that of each of the other doctors and with the

conclusion of the judge, must remove any basis upon which the diagnosis of death can be challenged.

96. Lastly, the judge said at [32] that:

‘If a patient is brain stem dead then there are no best interests to consider. Once those criteria are met the patient has irreversibly lost whatever one might define as life...’

I agree. Once a court is satisfied on the balance of probabilities that, on the proper application of the 2008 Code (and where appropriate the 2015 Guidance), there has been brain stem death there is no basis for a best interests analysis, nor is one appropriate. The court is not saying that it is in the best interests for the child to die but, rather that the child is already dead. The appropriate declaration is that the patient died at a particular time and on a particular date without more.”

The reference to further tests and mention of the situation in the USA refers to a suggestion that the court should consider further testing to conform with the approach to this issue as followed in that country. In the USA clinicians are required to diagnose “whole-brain death” as opposed to “brain-stem death.”

[29] Before leaving this analysis of the case law, I would like to make some brief comments about the standard of proof. Sir Andrew McFarlane at [96] in *Re M* correctly refers to this as being on the balance of probabilities. This is a statement of the law which is very well established. There are only two recognised standards of proof – beyond a reasonable doubt in the criminal law and on the balance of probabilities in the civil law. It has been recognised that this may raise issues when civil courts are dealing with allegations of what would also constitute criminal conduct (*e.g.* sexual assault or fraud). Similar issues arise in cases such as this where there are extreme consequences following on from the court’s decision.

[30] However, the balance of probabilities standard does not mean in a case such as this that the court will proceed on the basis that a patient is more likely than not to be dead, or to put it in perhaps the starkest of terms, there is a 51% chance that the patient is dead.

[31] To assuage the concerns of family members and other interested members of the wider public it is important to note several matters. Firstly, the courts in cases such as this are being asked to determine whether a person is dead. That is a basic and core fact and it is not open for a court to find that the person is probably dead. It is therefore a straightforward binary choice.

[32] Secondly, it is recognised by the law that in a case such as this although there

is not a higher standard of proof in play, the context is such that cogent evidence is required. This is best exemplified in the speech of Lord Nicholls in *Re H* [1996] AC 563 at 586H where he stated:

“The inherent probability or improbability of an event is itself a matter to be taken into account when weighing the probabilities and decided, whether on balance, the event occurred. The more improbable the event, the stronger must be the evidence that it did occur.”

Lord Nicholls then quoted, with approval, the comments of Ungood-Thomas J in *Re Dellow's Will Trusts* [1964] 1 WLR 451 at 455:

“The more serious the allegation the more cogent is the evidence required to overcome the unlikelihood of what is alleged and thus prove it.”

[33] In RL's case, he is currently exercising cardiorespiratory function (albeit with the assistance of a machine) and therefore the court must approach the case on the basis that he is alive and will therefore seek out cogent evidence to overcome an unlikelihood that he is dead.

[34] Finally, the guidance provided by the 2008 Code does not make any provision for a determination by doctors of brain-stem function to be on the balance of probabilities, in other words that there is probably no brain-stem function. It is, like the decision of the court, a binary diagnosis - there is either brain-stem function or there is no brain-stem function. The recommended multiplicity of tests is required to be carried out by first one doctor and then repeated, independently, by another. It is only when each of the tests carried out by both doctors establishes a negative result that the guidance provides for a diagnosis of a lack of brain-stem function.

[35] This is therefore a case which is similar to the one that was dealt with in *B v Chief Constable of the Avon and Somerset Constabulary* [2001] 1 WLR 340 where Lord Bingham commented at [30] and [31]:

“It should be ... clearly recognised ... that the civil standard of proof does not invariably mean a bare balance of probability ... The civil standard is a flexible standard to be applied with greater or lesser strictness according to the seriousness of what has to be proved and the implications of proving those matters ... In a serious case ...the difference between the two standards is, in truth, largely illusory.”

The evidence of Dr AB and Dr CD

[36] Dr AB and Dr CD gave evidence to describe how they on 20 April 2022

carried out the procedure for the diagnosis and confirmation of cessation of RL's brain-stem function. This procedure is set out in Appendix 1 of the 2008 Code and the purpose is to test for brain-stem reflexes. The procedure involves a preliminary diagnosis of irreversible brain damage, then an elimination of potential reversible causes for this condition, and finally the carrying out of tests to confirm the absence of brain-stem function.

[37] Both doctors have completed a report which follows the procedure set out in Appendix 1 of the 2008 Code. That report reflected their individual findings and not any joint or collaborative findings.

[38] Both were satisfied that RL had suffered a hypoxic ischaemic brain injury supported by the evidence contained in the MRI scan of RL's brain on 7 April 2022. It is recorded that RL did not fall within any 'red flag' patient group that would give rise to the exercise of diagnostic caution.

[39] Next, each doctor carried out various tests to exclude the possibility that cardiovascular and respiratory instability was a cause of the observed coma and apnoea. These included testing for the presence of depressant drugs, neuromuscular blocking drugs, hypothermia or a metabolic disturbance.

[40] There then followed the series of tests which can be summarised as follows:

- Pupil reaction to light
- Eyelid movement on touching of each cornea
- Eye movement following injection of ice cold water over one minute into each ear
- Presence of gag reflex
- Presence of cough reflex when a suction catheter is passed down the trachea
- Any motor response in a cranial nerve when supraorbital pressure is applied

Both doctors recorded negative findings.

[41] Finally an apnoea test was carried out. This involved continuous observation of RL after disconnection from the ventilator over a period of 5 minutes. This was carried out over two separate periods. No spontaneous respiration was observed by either doctor during these periods. Measurements taken before and after each test of the partial pressure of carbon dioxide in RL's arterial blood and before each test of arterial blood gas were all within appropriate parameters.

[41] Both doctors, having concluding their separate tests were of the view that there was no need for any ancillary investigations and both were of the opinion that

death could be confirmed following irreversible cessation of brain-stem function. Dr AB concluded his tests at 15:12, and Dr CD concluded his tests at 15:59. The 2008 Code provides that in such an event as this the assumed time of death is the time of the conclusion of the first tests.

The evidence of Professor EF

[42] Professor EF prepared a brief report for the hearing. He gave evidence and was cross-examined. He does not accept the concept of brain-stem death expressing the view that it has more to do with preservation of human tissue and organs prior to potential transplant. He referred, in general terms, to numerous occasions (numbered as approximately 1,000) of him “awakening” a patient from cerebral coma, and one specific incident of him in 1999 “restoring the life” of a patient considered to be dead. No detail was provided save for a reference to a book authored by Professor EF entitled (in English translation) – *Black Book of the so-called brain death*” (2022).

[43] Professor EF took no issue concerning the evidence of Dr AB and Dr CD, the nature of the tests they carried out, and the results of the tests. His case was that even if there was a diagnosis of cessation of the brain-stem function that was not evidence of death. His view was that he would “treat every patient without time limits with the described methods of comprehensive neuro-habilitation and neuro protection.”

[44] He did state that as a result of a telephone conversation with RL’s mother and the exchange of SMS text messages, and on viewing photographs of RL’s face and eyes and an image of the bedside monitor it is wrong to “judge him as dead.” He indicated that he did not have access to RL’s medical notes and records, he did not seek to see them and he declined to speak to Dr AB (or any other treating doctor) as he considered that this would not be productive.

[45] As for his medical background, Professor EF is a qualified medical practitioner but is not a neurologist or intensive care specialist. He described himself as a “medical physiotherapist.” He acknowledged that he had been the subject of professional misconduct disciplinary proceedings relating to a presentation he had given to a conference which he said disturbed some people. It was difficult in the circumstances to get full details about these proceedings but I consider that they have arisen as a result of Professor EF’s opinions which could be classified as controversial when set against current mainstream medical opinion. Given the fact that professional misconduct was asserted, this would have been more than simply holding a contrary opinion, but must have included reprehensible conduct.

[46] It is not the first time Professor EF has given evidence before the courts in Northern Ireland. He appeared before O’Hara J in 2014 in the case of *Re M* [2014] NIFam 3 a ‘best interests’ decision relating to the proposed withdrawal of ventilation from a 5 month old baby. The judgment gives more detail about Professor EF’s qualifications and expertise. O’Hara J made some pertinent remarks about the role

of Professor EF (referring to him as Professor Z) in the case at [28] and [29] and it is beneficial to set out these remarks in full –

“[29] 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.

[30] 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.”

Consideration

[47] The 2008 Code is a product of the joint efforts of the Royal Colleges of Medicine. Since its publication it has become the only established statement which

reflects the consensus of medical opinion concerning the diagnosis of death in the United Kingdom. In the period since publication it has not been the subject of any serious challenge. Debate still continues in medical circles concerning the USA's concept of "whole-brain death" but insofar as that has any relevance to this case, and it was not raised on behalf of the parents or by the Official Solicitor, the concept of "brain-stem death" is to be considered as the only proper determination of death (as per *Airedale NHS* and confirmed by *Re M*).

[48] I have considered the views of Professor EF. I acknowledge that his view concerning brain-stem death is a genuinely held view, but he offers no cogent or authoritative evidence that would challenge the consensus of opinion established by the 2008 Code. I have no reason to doubt his assertion that he has awakened a number of patients from coma. The exact number will be a matter of medical record. However being in a coma, *i.e.* a state of prolonged unconsciousness, is significantly different from having no brain-stem function. Professor EF offers one example of a named individual "restored to life" after being considered dead in 1999 and refers to "many such patients" but offers no evidence for the court to consider. In particular he does not state the basis on which that patient was considered to be dead. The fact that professional misconduct proceedings occurred in 2015 would also suggest that these, and presumably similar, assertions are not only rejected by the medical profession in FC, but Professor EF's statements and his conduct were considered to be reprehensible. I share the views expressed by O'Hara J in *Re M* in 2014. The intervention has only added to the distress of the parents. It is perfectly understandable why the parents, in their desperate state of mind, should seek out any solution to their predicament, but Professor EF has only added to their grief by potentially raising a totally unrealistic and false hope.

[49] No challenge is made to the nature and purpose of the tests carried out by Dr AB and Dr CD. They have confirmed that RL, on 20 April 2022, had no longer any brain-stem function.

[50] I therefore consider that the Trust has proved, to the requisite standard, that at the time of the first test being carried out, there was no evidence indicating brain-stem function, and as a consequence RL was clinically dead.

[51] In the circumstances any further medical support and intervention would have no bearing at all and it is appropriate that it should be withdrawn, with no further intervention provided for the support of life.

Conclusion

[52] I will therefore grant the relief sought by the Trust namely a declaration that RL died at 15:12 on 20 April 2022. I also grant permission to the Trust to cease mechanical ventilation, to extubate RL, to cease the administration of medication and not to attempt any CPR. Finally, I declare that these actions and inactions are to be considered lawful.

[53] To allow the parents of RL to consider the implications of this decision I agreed to stay the operation of the order for 24 hours.

[54] Before concluding my remarks I would like to place on record my appreciation for the assistance provided to the court by all the counsel in this case. They dealt with all aspects of the case both conscientiously and expeditiously, and with sensitivity. I would particularly like to commend Mr Patrick Gillen, counsel for the parents, for his input to this case bearing in mind the need to consult and advise the parents of RL who were understandably in a most distressed state, being in a foreign state, unable to converse in their mother tongue, and having to cope with these most catastrophic of circumstances.

Postscript

There was no further application to the court and no appeal against this order. I have been advised that with the agreement of RL's parents, and in their presence, RL was removed from the ventilator at 18:00 on 27 April 2022.