BRAIN DEATH AND THE LAW

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Death draws the final curtain on all our lives. How that occurs, and the manner in which we should approach death, has provided grist to the mill of philosophers, poets, politicians, social commentators and comedians down the ages and it is doubtful that any conclusion common to all humankind will ever be reached. Whether we think Socrates was correct to say that 'death may be the greatest of all human blessings', or that Dylan Thomas was right to urge us, when faced with death, to 'rage, rage against the dying of the light', is a matter of personal philosophy and morality on which views diverge and always will. The law injects itself into this debate largely as a result of the enormous strides modern medicine has made in its ability to prolong life and postpone death. This has changed our understanding of death itself. It can no longer be viewed as simply the cessation of the heart beating and the lungs breathing, because these can be maintained artificially, so the medical profession now asks whether the brainstem is dead in the sense of showing no activity.[1]

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In some cases it is now apparently possible, with the use of the ventilator, to sustain a beating heart even though the brain stem, and therefore in medical terms the patient, is dead; "the ventilated corpse."[2]

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It is...simpler to visualise the brain, the heart and the lungs as forming a 'cycle of life' which can be broken at any point. Looked at in this way, it is fundamentally wrong to speak of two types of death, that is cardiorespiratory or brain death: it is simply that different criteria and different tests can be used for identifying that the cycle has been broken… [W]hile we would normally use the heart and the lungs as the medium through which to make the diagnosis, we are forced to turn to the brain when the natural functional condition of either is obscured by the intervention of a machine...[3]

INTRODUCTION

1. There is no statutory definition of death in England and Wales. Instead, the courts have approved the medical consensus, first set out in writing in 1976, that death can occur either when the circulatory and respiratory systems stop working, or when the

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[1] **Minister of Justice and Correctional Services v Stransham-Ford's Estate** [2017] 2 LRC 390
[2] **Airedale NHS Trust v Bland** [1993] UKHL 17 per Lord Browne Wilkinson
[3] Principles of Medical Law, Grubb at al, 22.10.

brain stem stops functioning – known either as brain stem death or death by neurologic criteria (DNC).

2. The 1976 statement was last updated in 2008, and has been approved by the courts up to and including the Court of Appeal. It is cited in other guidance issued by the medical profession, including the RCPCH guidance ***Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children; a Framework for Practice*** which has itself also been approved by the Court of Appeal.[4]

   This has led to something of a self-reinforcing circle, where the medical profession relies on the guidance as having been endorsed by the courts and the courts rely on the guidance as reflecting the consensus view of the medical profession. There has never been a Law Commission enquiry or an attempt at an Act of Parliament to put the definition of death on a statutory footing, and so there has not been any wider opportunity to consider whether, for example, there should be a different approach taken where people hold religious views that do not coincide with the medical consensus.

3. In contrast, in other jurisdictions, statutory definitions have been imposed – most notably in the USA, where all of the States have adopted a 'whole brain death' approach, rather than brain-stem death, and most have incorporated the definition into statute, but with variations in the language used. Pressure is mounting for revisions to the definition used in the USA that would bring the definition more in line with the UK approach.

4. In this paper, we set out the current medical guidance, for reference and consider the cases in which the issue of brain death has been arisen in this jurisdiction, and abroad. We then summarise the procedural considerations that apply, and pose some questions about the future development of the law in this area.

MEDICAL GUIDANCE

5. In 1976, the BMJ published a "Statement issued by the honorary secretary of the Conference of Medical Royal Colleges and their Faculties in the United Kingdom" entitled *Diagnosis of Brain Death.*[5] The statement set out diagnostic criteria for brain death, and explained why such criteria were needed:

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[4] **Re A (A Child)** [2016] EWCA Civ 759

[5] https://www.bmj.com/content/bmj/2/6045/1187.full.pdf

With the development of intensive care techniques and their wide availability in the United Kingdom it has become commonplace for hospitals to have deeply comatose and unresponsive patients with severe brain damage who are maintained on artificial respiration by means of mechanical ventilators. This state has been recognised for many years and it has been the concern of the medical profession to establish diagnostic criteria of such rigour that on their fulfilment the mechanical ventilator can be switched off, in the secure knowledge that there is no possible chance of recovery.

There has been much philosophical argument about the diagnosis of death, which has throughout history been accepted as having occurred when the vital functions of respiration and circulation have ceased. With the technical ability to maintain these functions artificially, however, the dilemma of when to switch off the ventilator has been the subject of much public interest. It is agreed that permanent functional death of the brain stem constitutes brain death and that once this has occurred further artificial support is fruitless and should be withdrawn.

6. The statement makes no reference to differing religious views about brain death, but assumes that withdrawal of ventilation where brain death has occurred is in the interests of relatives: '*It is good medical practice to recognise when brain death has occurred and to act accordingly, sparing relatives from the further emotional trauma of sterile hope.'*

7. The diagnostic criteria are said to be '*sufficient to distinguish between those patients who retain the functional capacity to have a chance of even partial recovery from those in whom no such possibility exists.'* The criteria, all of which must coexist, are:

    a. The patient is deeply comatose, and other explanations for this state such as hypothermia or the effect of medication have been ruled out.
    b. The patient is being maintained on a ventilator because spontaneous respiration had previously become inadequate or had ceased altogether.
    c. There should be no doubt that the patient's condition is due to irremediable structural brain damage. The diagnosis of a disorder which can lead to brain death should have been fully established.

8. The statement sets out tests for confirming brain death: that all brain-stem reflexes should be absent (for example eye movements, motor responses and the gag reflex), though spinal cord reflexes may continue to be present, or may return after an initial absence. The tests should be repeated if appropriate, but other confirmatory investigations such as EEG are not necessary. The statement advises that

"Experienced clinicians in intensive care units, acute medical wards, and accident and emergency departments should not normally require specialist advice. Only when the primary diagnosis is in doubt is it necessary to consult with a neurologist or neurosurgeon. The decision to withdraw artificial support should be made after all the criteria presented above have been fulfilled and can be made by any one of the following combinations of doctors: (a) a consultant who is in charge of the case and one other doctor; (b) in the absence of a consultant, his deputy, who should have been registered for five years or more and who should have had adequate experience in the care of such cases, and one other doctor."

9. There were later updates to this statement, the most recent of which is the 2008 publication "*A code of practice for the diagnosis and confirmation of death*" from the Academy of Medical Royal Colleges.[6] The 2008 Code says that it is a '*statement of current practice in the diagnosis and confirmation of death'* and further that:

   It does not (and could not) seek to provide guidance for every single clinical situation where a doctor is required to diagnose death or to be a comprehensive statement of clinical and/or legal obligations for medical staff towards their patients in this complex area of practice. Doctors and other healthcare workers should bear in mind the need to consider the Guidance carefully and, using their own clinical judgment, to consider whether it is appropriate to any individual case.

10. The 2008 Code explains that death can occur in one of two ways: following the irreversible cessation of brainstem function, and following cessation of cardiorespiratory function. The former, which this paper is concerned with, is defined as follows:

    The irreversible cessation of brain-stem function whether induced by intra-cranial events or the result of extra-cranial phenomena, such as hypoxia, will produce this clinical state and therefore irreversible cessation of the integrative function of the brain-stem equates with the death of the individual and allows the medical practitioner to diagnose death.

[6] https://www.aomrc.org.uk/reports-guidance/ukdec-reports-and-guidance/code-practice-diagnosis-confirmation-death/

11. The 2008 Code makes clear that brain stem death, not whole brain death, is the relevant test:

> *When a patient is comatose, apnoeic and receiving artificial ventilation of their lungs, the criteria for determining irreversible cessation of brain-stem function will be the irreversible loss of brain-stem reflexes, diagnosed by clinical neurological testing*

12. The 2008 Code differentiates PVS from brain-stem death, noting that patients who are brain-stem dead "*cannot continue to breathe unaided without respiratory support, along with other life-sustaining biological interventions*. *This also means that even if the body of the deceased remains on respiratory support, the loss of integrated biological function will inevitably lead to deterioration and organ necrosis within a short time.*" This suggests that it should be evident within a short period whether a patient is in PVS or is brain-stem dead, regardless of what clinical testing has been carried out, and difficulties with differentiating between conditions such as is encountered in relation to PVS/MCS should not arise. The Code advises that

> … *Even if ventilation and cardiovascular support are continued, both adults and children will ultimately suffer cessation of heartbeat. Often this occurs within a few days, but may take weeks or even months if aggressive support is maintained, although there are no verified reports of patients recovering brain-stem function during this time.*

13. The 2008 Code is clear that brain-stem death does not mean the cessation of all neurological activity. However, '*where such residual activity exists, it will not do so for long due to the rapid breakdown of other bodily functions*.'

14. The Code notes that in the absence of a statutory definition of death, the courts have adopted the criteria set out in the 1976 statement '*as part of the law for the diagnosis of death*'.[7]

15. When the patient is in a coma, and before brain-stem death has been confirmed, the Code says that treatment decisions must be made in the patient's best interests. But once brain-stem death is present, '*the death of the individual has occurred….the patient is dead even though respiration and circulation can be artificially maintained successfully for a*

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[7] The Code cites in support of this statement two cases: **Re A (A Minor)** (1992) MLR 3, 303 and **Re TC (A Minor)** (1994) Medical Law Reviews 2, 376. Both in turn rely on the House of Lords' decision in **Bland** as accepting the medical consensus as to brain stem death (see further below).

limited period of time.' The Code makes clear that it '*refers both to an individual before death, who lacks capacity and after death has been diagnosed and confirmed, when the question of best interests no longer arises*.'

16. The Code lists the conditions necessary for the diagnosis and confirmation of death in the brain damage context (as opposed to cessation of circulation/respiration) as follows:

    - Aetiology of irreversible brain damage
    - Exclusion of potentially reversible causes of coma
    - Exclusion of potentially reversible causes of apnoea

17. Guidance is given about clinical tests to determine brain-stem death, which are centred on the absence of brain-stem reflexes. The tests include putting cold water in the ear, and testing for a gag reflex with a suction catheter or spatula. As in the 1976 statement, additional confirmatory neurophysiological or imaging investigations are not mandated, although some specific circumstances are given where they may be appropriate, because of difficulties in carrying out the clinical tests.[8]

18. In 2014, the World Health Organization endorsed a single operational definition of human death:

    "the permanent loss of capacity for consciousness and all brainstem functions, as a consequence of permanent cessation of circulation or catastrophic brain injury."

Very young babies

19. The 2008 Code advises (based on a 1991 report) that in children aged under two months, "*it is rarely possible confidently to diagnose death as a result of cessation of brain-stem reflexes, and below thirty-seven weeks of gestation the criteria to establish this cannot be applied*."

20. In 2015, the RCPCH published a clinical guideline addressing the position of young babies.[9] It recommended that the 2008 conditions should be fulfilled before

[8] Note that in other countries, confirmatory tests are required – see *Principles of Medical Law* at 22.30 and the references to that paragraph, and the Court of Appeal decision in **Re M** referring to evidence as to practice in America.

[9] https://www.rcpch.ac.uk/resources/diagnosis-death-neurological-criteria-dnc-infants-less-two-months-old-clinical-guideline

diagnosing brain-stem death (otherwise known as DNC or death by neurological criteria). An extra condition was added for a specific subset of patients:

> *In post-asphyxiated infants, or those receiving intensive care after resuscitation, whether or not they have undergone therapeutic hypothermia, there should be a period of at least 24 hours of observation during which the preconditions necessary for assessment for DNC should be present before clinical testing for DNC. If there are concerns about residual drug-induced sedation, then this period of observation may need to be extended.*

21. The same clinical examination criteria are recommended (absent brain stem reflexes, absent motor responses and so on) but with a modification to the test for respiratory responsiveness, to reflect the immaturity of the newborn infant's respiratory system.

22. The RCPCH framework '*Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*',[10] also published in 2015, includes the following:

> *The RCPCH believes that there are three sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, because treatments cannot provide overall benefit:*
>
> *<u>I When life is limited in quantity</u>*
> *If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:*
>
> *Brain stem death, as determined by agreed professional criteria appropriately applied*

23. Note the peculiar reference to brain stem death as being a circumstance where life is limited in quantity, and the equating of a decision to cease treatment to a best interests decision. Later on, the document says "*When death is diagnosed following formal confirmation of brain stem death by agreed medical criteria, intensive technological support is no longer appropriate and should be withdrawn, unless organ donation is being considered.*" It also provides the following guidance in relation to disputes with parents:

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[10] Larcher V, Craig F, Bhogal K, et al. Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice. *Archives of Disease in Childhood* 2015. https://adc.bmj.com/content/100/Suppl_2/s1

> "*Benefits may be so far outweighed by burdens that it would not be ethically or morally appropriate to provide treatment even if parents request it. This applies when the child is brain dead*."

24. The RCPCH framework document also says that a second opinion is required regarding the diagnosis of brain stem death: "M*any major medical decisions require a factual second opinion for legal reasons as well as clinical assurance, for example, termination of pregnancy, brain stem death*."

25. A possible explanation for the use of best interests terminology is that until the 2015 clinical guideline, brain stem death was not used as a method of establishing death in young babies. The Nuffield Council on Bioethics report on *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*,[11] published in 2006, explained that:

> *It is very unusual for a newborn baby with the common types of neonatal brain injury and abnormality that are observed at birth to meet the formal criteria for brain death, even after severe brain injury. We note therefore that when withdrawal of life support is considered for critically ill babies, the child is not brain dead but legally alive.*

CASELAW

Airedale NHS Trust v Bland [1993] AC 789 (4 February 1993)

26. Tony Bland was left in a vegetative state following injuries he sustained in the Hillsborough disaster. A question - which at that time was a novel moral and ethical one – arose as to whether it was lawful for his artificial nutrition and hydration to be withdrawn.

27. In the course of their judgments, a number of the members of the House of Lords commented upon the new moral and ethical dilemmas created by modern medicine. The views are best encapsulated by Lord Goff, at 878:

> "*Recent developments in medical science have fundamentally affected these previous certainties. In medicine, the cessation of breathing or of heartbeat is no longer death.*

[11] https://www.nuffieldbioethics.org/publications/neonatal-medicine-and-care

By the use of a ventilator, lungs which in the unaided course of nature would have stopped breathing can be made to breathe, thereby sustaining the heartbeat. Those, like Anthony Bland, who would previously have died through inability to swallow food can be kept alive by artificial feeding. This has led the medical profession to redefine death in terms of brain stem death, i.e., the death of that part of the brain without which the body cannot function at all without assistance. In some cases it is now apparently possible, with the use of the ventilator, to sustain a beating heart even though the brain stem, and therefore in medical terms the patient, is dead; "the ventilated corpse."

I do not refer to these factors because Anthony Bland is already dead, either medically or legally. His brain stem is alive and so is he; provided that he is artificially fed and the waste products evacuated from his body by skilled medical care, his body sustains its own life. I refer to these factors in order to illustrate the scale of the problem which is presented by modern technological developments, of which this case is merely one instance. The physical state known as death has changed. In many cases the time and manner of death is no longer dictated by nature but can be determined by human decision. The life of Anthony Bland, in the purely physical sense, has been and can be extended by skilled medical care for a period of years.

To my mind, these technical developments have raised a wholly new series of ethical and social problems. What is meant now by "life" in the moral precept which requires respect for the sanctity of human life?"

28. The House of Lords' judgment in **Bland** has been taken as adopting the position that the law's view of death was the same as that of UK doctors – namely brain stem death. It is interesting to note that that endorsement arose in the context of a patient whose brain stem was alive, and are therefore strictly obiter. Nevertheless, these observations from **Bland** have been adopted as seminal and relevant in all subsequent cases.

Re A [1992] 3 Med LR 303 (27 January 1992)

29. A was a 19-month old infant, found by his doctors to be brain stem dead on 22 January 1992. The evidence of A's treating clinicians was that he was dead by the standards of their profession at that time, in that he was unresponsive to what has become the familiar battery of bedside brain-stem tests. An emergency protection order had been applied for, which complicated the question of parental responsibility, and the matter came before the court for urgent hearing five days later. The parents were apparently concerned that removal of A from the ventilator might compromise the quality of evidence concerning the cause of his death (there being an issue as to non-accidental injury) and wanted further time to arrange an independent examination of A.

30. In light of the medical evidence, the Judge held that A "*is now dead for all legal, as well as medical, purposes*". The judgment is very short and contains no reasoning as to why the legal and medical definitions of death should align. But given the circumstances of the judgment (delivered *extermpore* following an urgent afternoon hearing) and its relative age, it now seems remarkably prescient.

<u>TC (A Minor) (30 November 1993)</u>

31. **<u>TC</u>** also involved a young child, this time with spina bifida and hydrocephalus, found to be brain stem dead. The Judge observed that brain stem death was a well-understood diagnosis that had been subject to set criteria since the mid-1970s. Ordinarily, following diagnosis, life support would be withdrawn without the need for an application to the Court. The only complicating factor in the instant case was that the child had been a ward of the Court. But the Judge was satisfied, in the undisputed clinical circumstances of the case, that:

"…it would be wholly contrary to the interests of TC for her body to be subjected to what would seem to me to be the continuing indignity to which it is presently but properly subjected. I consider that the nursing and medical staff of this hospital have done all that could be done for the welfare and wellbeing of this child. TC may now be separated from the ventilation which supports her existence – not life – when the medical staff at the hospital consider it proper so to do."

<u>PP v Health Service Executive [2014] IEHC 622 (26 December 2014)</u>

32. NP was 15 weeks' pregnant when, on 29 November 2014, she collapsed unconscious and required intubation. By 3 December 2014 tests indicated that her brain stem had died. There had been a cerebral angiogram carried out which showed no evidence of blood flow in the brain. The hospital sought to treat NP's body for the duration of her pregnancy, in an attempt to attain foetal viability.

33. NP's father took the relevant public body to court, arguing that the prolonged somatic support measures were unreasonable and should be discontinued, because they were experimental in nature and had no proper basis in medical science or ethical principle. The debate turned on evidence of whether the unborn child could survive in such circumstances (it almost certainly could not).

34. A feature of Irish law is that the unborn have the constitutional guarantee of a right to life. The Court weighed up the fact that the current course of treatment was a "distressing exercise in futility" against the costs of that exercise to the dignity of the mother; the comfort of the family; and the ethical integrity of the medical staff delivering the treatment and concluded, firmly, that it was in the best interests of the unborn child for treatment to be withdrawn. The judgment includes distressing details of the physical state of NP's body, including the presence of an infected head wound relating to a medical intervention, a urinary tract infection, indications of pneumonia, swollen eyeballs, high blood pressure, and an observable a build up of fluid in the body.

Re A (A Child) [2015] EWHC 443 (Fam)

35. Child A was a 19-month old, healthy, boy who, on 6 February 2015, choked on a small piece of fruit. Within an hour the obstruction was removed operatively and cardiac output was re-established, and A was placed on a neuro-protective regime. Nevertheless, by 10 February 2015, tests showed the death of his brain stem.

36. The father, who was Muslim, questioned whether brain stem death was synonymous with clinical/legal death. He did not believe the two to be equivalent for reasons, so found the Judge, of his Muslim belief and his basic paternal instinct.

37. The Judge cited and relied on the 2008 Code of Practice and a 1991 "*Report of a working party of the British paediatric Association on the diagnosis of brain-stem death in infants in children.*" (a precursor to the 2015 RCPCH clinical guideline).

38. The case also featured a seemingly rather insensitive request by the Coroner to extubate and de-ventilate A and deliver his body up to the jurisdiction of the Coroner on the basis that A was now a dead body. The Judge found that that was inappropriate on a number of grounds, one of which was that:

> *"The facts of this case are a reminder once again that in a multi-cultural society there has to be recognition that people, particularly those with strong religious beliefs, may differ with medical professionals as to when death occurs. In the Christian, Muslim and Jewish faiths the concept of the "breath of life" has ancient and important resonance. It is hardly difficult to understand why the still breathing body is regarded as alive, even though "breath" may be entirely delivered by machine. An insistence on a legally precise definition of death to trigger the involvement of the Coroner, in such challenging circumstances is, in*

my judgment, so obviously wrong as to be redundant of any contrary argument."

39. The Judge appears to have given greater consideration, and more latitude, to religious views when considering the Coroner's jurisdiction than when considering whether A had died.

Oxford University NHS Trust v AB (A Minor) & Ors [2019] EWHC 3516 (Fam)

40. AB was a 14-year old girl found hanging in her home on 17 October 2019. She was discovered and treated but her brain had been without oxygen for 31 minutes. She was from a profoundly religious Christian family. By 22 October 2019, it was confirmed that her brain stem was dead.

41. The Judge (Francis J) referred to **Re A** and noted the reliance placed in that case upon the 2008 Code of Practice. Francis J did the same, and concluded on the basis of the evidence that the criteria in the Code of Practice were met. He therefore declared that AB was dead, and that as such the life support equipment could be removed. In doing so, he observed that:

> *"AB's parents have faith. This is not the first case and it will not be the last case where faith has conflicted with science. I am not going to make judgments about that. All I am going to say is that it is completely clear on the basis of the medical evidence, which has been so properly and completely set out to me, that there is no prospect whatsoever of AB reviving for all of the reasons that I have set out."*

42. Francis J also made a declaration sought by the Trust erroneously – that it was "*lawful and in AB's best interests for all care and treatment to be withdrawn*".

Re M (Declaration of death of a child) [2020] EWCA Civ 164

43. This recent case is the first occasion on which the issues have reached the Court of Appeal. Once again, the case involved the brain stem death of a young Muslim child.

44. The judgment, delivered by the President of the Family Division (Sir Andrew McFarlane P), identifies the issue for the court as being (a) whether the patient is dead,

according to the DNC tests and relevant clinical guidance; and (b) if so, whether the ventilator can be removed (paragraph 23).

45. There are three subtleties in this set of issues. The first is that, once the Court is no longer carrying out a best interests balancing exercise, it is simply making a declaration as to a state of affairs (known as a "Part 8 declaration", after the part of the Court's civil procedural rules which apply in such cases). Second, the state of affairs for which the Court is searching is whether or not the relevant clinical guidelines have been satisfied. That is an objective question, to be decided on the strength of the medical evidence. Third, by separating out the two issues, the Court of Appeal may be taken to be implying that there are circumstances in which it may not be permissible for the ventilator to be removed notwithstanding the clinically certified death of the patient. However, on the current state of the law it is virtually impossible to conceive of circumstances in which, if the answer to the first question is Yes, the answer to the second question would not also be Yes.

46. Note that in the old case of **Re TC**, the court declined to direct the withdrawal of ventilation, saying '*TC may now be separated from the ventilation which supports her existence – not life – when the medical staff at the hospital consider it proper so to do…. I would adopt and repeat what Johnston J said at p 6 of his judgment [in Re A]:*

> "*The function of the court in this delicate jurisdiction is to assist by clarifying the position and not to usurp the discretion of the doctors to do what they think is best in the difficult circumstances in which they are placed.*" '

47. At paragraphs 24 and 96 the Court of Appeal emphasised that the relevant question in such circumstances is not one of best interests, as the court is essentially dealing with a body rather than with a living human. The question is a purely objective one about whether the diagnostic criteria have been met.

48. On the appeal, the parents sought to cast doubt on the reliance placed by the English courts upon the consensus view in UK medicine that brain-stem death is death. They pointed in particular to US guidance, which depends on a diagnosis of whole brain death and requires a more searching battery of tests. It was also argued that in any event, given the gravity of the issue, a wider assortment of investigations ought to be carried out. The Court rejected that argument, relying once again upon the authority of **Bland** that English law defines death as being brain stem death.

49. The evidence in **Re M** was that the child's brain had liquified and no longer had any structures resembling a normal brain. There was unanimous medical evidence that M was brain stem dead, and some additional confirmatory tests had been carried out.

50. Finally, it is also worth noting the Court of Appeal's observations about the way in which such cases may be reported, given the large amount of sometimes negative publicity and attention that recent high profile cases have caused for trusts and clinicians. The Court held at [102] that:

"The manner in which social media may now be deployed to name and pillory an individual is well established and the experience of the clinicians treating child patients in cases which achieve publicity, such as those of Charlie Gard and Alfie Evans, demonstrate the highly adverse impact becoming the focus of a media storm may have on treating clinicians. The need for openness and transparency in these difficult, important and, often, controversial cases is critical but can, in the judgment of the court, be more than adequately met through the court's judgments without the need for identifying those who have cared for Midrar..."

Observations

51. For thirty years, courts have consistently, and without significant hesitation, reached the conclusion that for legal purposes death occurs when doctors diagnose brain stem death according to the standards of their profession. No doubt has been cast upon the manner in which brain stem death is diagnosed, but some have tried to argue – usually on religious grounds – that life support systems should be maintained notwithstanding that a patient is brain dead. That argument has always been given short shrift, and it seems from a consistent line of cases across nearly three decades that that is unlikely to change. Nevertheless, it remains possible to identify two recognisable moral views: on the one hand, the dignity of the deceased; on the other, a religious view as to the sanctity of life. It is not entirely self-evident why, in a multicultural and multi-faith society, the former should inevitably outweigh the latter in all cases. Given the immense gravity of the issue, the foundations for that assessment in obiter comments in **Bland** and medical guidance that was not drawn up on the basis of wider consultation outside the medical profession seem relatively weak. Nevertheless, the courts have so far declined the opportunity to undertake a detailed balancing exercise of those two competing values.

52. The following features appear repeatedly in the cases. None of them, to date, have dislodged the Court's view that the medical definition of death is the appropriate one to adopt as a matter of law:
    a. A moral view, often rooted in Christian, Jewish, or Muslim, belief that as long as a body is breathing, even if the breath is artificial, it is in some sense alive. Conversely, that the withdrawal of treatment would be "killing" the patient.
    b. Evidence of limb movement or eye blinking. Parents attach great importance to this, but it is typically the result of spinal reflexes rather than cranial activity.
    c. An acceptance of the diagnosis but a desire to remove the patient to a country where they will be kept on life-support indefinitely due to a different legal approach to ventilation after brain stem death.
    d. It will sometimes be argued that certain tests should not be carried out (if the likely outcome is that they will confirm the diagnosis); that further tests should be carried out (either from a sense of hope that they will undermine the diagnosis, or that arranging the tests will postpone the moment of death); or that a second opinion should be obtained (for similar reasons).

Other jurisdictions

53. The parents in **Re M** sought to persuade the court to take a different approach on the basis that other jurisdictions, in particular the USA, adopt a definition of whole brain death rather than brain stem death. In fact, the position in the USA is rather more complicated as different approaches and different statutory definitions apply in different States. A comprehensive review can be found in *Determination of Death by Neurologic Criteria in the United States: The Case for Revising the Uniform Determination of Death Act*.[12]

54. In briefest summary, the President's Bioethics Commission in the US proposed a model statute in the 1980s which applied two alternative standards for identifying death: (1) "irreversible cessation of circulatory and respiratory function" or (2) "irreversible cessation of all functions of the entire brain, including the brainstem" in "accordance with accepted medical standards." The Uniform Determination of Death Act was proposed, and aimed to ensure consistency between the States, by defining death but permitting doctors to develop the relevant medical standards for determining its presence. The provisions of the UDDA were not adopted uniformly throughout the USA, and have in any event been interpreted differently in different courts. The authors note that these variations include: *(1) legal criteria for determination*

[12] Lewis et al, Journal of Law, Medicine and Ethics, 2019 vol 47 issue 4

of death; (2) accepted medical standards for determination of death by neurologic criteria; (3) response to family objections to determining brain death; and (4) response to family objections to terminating organ support after determination of brain death.

55. A further complication arose when New Jersey decided to allow an opt-out for people with religious beliefs. Their legislation provides that the "*death of an individual shall not be declared upon the basis of neurological criteria…when the licensed physician authorized to declare death has reason to believe…that such a declaration would violate the personal religious beliefs of the individual*."

56. This led to the highly publicised case of Jahi McMath, a young girl who suffered a catastrophic event following elective surgery, and was declared brain dead. Her parents objected and moved her to New Jersey, where she was no longer considered to be dead, and was kept on ventilation and PEG fed for around 4 years before she eventually died of other organ failure. Her mother sought to argue that signs of physical movement were evidence she did have a functioning brain, as did the fact that she started menstruating after being declared dead.

57. In Canada, the court recently declined to decide whether religious beliefs should be accommodated in relation to brain stem death, noting that this might be a question better left to the legislature than the courts.[13]

PROCEDURE

58. There is nothing in the Children Act 1989 or the Mental Capacity Act 2005 which conveys a power on any person, including the court, to make decisions about a dead body. The inherent jurisdiction of the High Court has, however, been invoked to resolve burial disputes in respect of both children and adults. See **Re K (A Child: deceased)** [2017] EWHC 1083 (Fam) and the cases cited therein.

59. Procedurally, therefore, where clinical tests have confirmed brain stem death, in the event of a dispute, an application should be made to the High Court for a declaration that the individual is dead. As noted by the Court of Appeal in **Re M**, there is no basis for any best interests declaration to be made in respect of a person who is dead. If the person is dead, then withdrawal of ventilation must follow, since there is a common law obligation on the personal representatives of the deceased (and ultimately a

[13] McKitty v. Hayani, 2019 ONCA 805 (CanLII),

statutory obligation on the relevant local authority) to arrange for the proper and expedient disposal of the body (see **Re K**).

60. A recent case before Hayden J provides an example – proceedings were issued in the Court of Protection before the diagnosis of brain stem death had been confirmed. Once the diagnosis was confirmed, the proceedings were converted to a part 8 application in the High Court.

61. It is difficult to see what role there could be for the Official Solicitor or a Cafcass-appointed guardian in such cases, as a dead person cannot be a party to proceedings – this has not stopped a guardian being appointed in recent cases, notwithstanding the unanimous medical evidence of brain stem death.

62. The form of order is as set out in **Re M** – a declaration that the person is dead, and the time and date of their death: "*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 it already dead. The appropriate declaration is that the patient died at a particular time and on a particular date without more.*"

63. Following the Court of Appeal's endorsement of reporting restrictions preventing the identification of medical staff, it is likely that more such applications and orders will be made in subsequent cases.

64. Attempts at mediation or other forms of alternative dispute resolution are, as always, encouraged by the courts, but the particular nature of the individual's position in such cases means that applications to the court should not be delayed, and should be progressed in tandem with other attempts at resolution.

65. The evidence required in support of the application will be confirmation that the relevant Codes and guidance have been followed, the outcome of the clinical tests and the supporting contemporaneous medical records, and any second (or third) opinions obtained. If additional tests have been conducted, despite not being mandated, they should also be put before the court.

66. It is, as the Court of Appeal pointed out in **Re M**, impossible to imagine any other outcome where there is a consensus of medical opinion as to the existence of brain stem death than an order confirming the same. Unless there is a dispute between

clinicians, the result of the court application is inevitable. One could imagine matters proceeding in a similar way to withdrawal of CANH in PVS patients, so that a clear checklist is set out which, if fully complied with, results in an application being determined by the court on the papers, without requiring an oral hearing which can result in only one answer.

QUESTIONS

67. Though the current legal position is clear, there are numerous questions raised by the diagnosis of brain stem death.

Should a different approach be permitted for people who do not recognise brain stem death as death for religious reasons?

68. What do the major religions actually say about brain stem death? The caselaw does not assist with understanding the perspectives of different religions, as they are not a consideration that the court has engaged with.

69. In *Brain Death and Islam: The Interface of Religion, Culture, History, Law, and Modern Medicine*,[14] the authors refer to the First World Meeting on Transplantation of Organs in 1969, saying that "*representatives of the Protestant, Catholic, Jewish, and Muslim faiths discussed ethicoreligious issues inherent with acceptance of such a definition of death. The consensus was that cerebral death was a reasonable concept fully within the province of the physician to identify.*"[15]

70. The article cites Pope Benedict XVI:

> *There is no "right" kind of death. When meeting at a final common endpoint, death, the order in which heart, lung and brain cease to function do not define different deaths. There are, however, different forms of death and most people are more comfortable and obviously used to the traditional "cardio-respiratory arrest" form of death.*
> *[…]*

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[14] Chest. 2014 Oct; 146(4): 1092–1101.

[15] Silverman D. Cerebral death—the history of the syndrome and its identification. Ann Intern Med. 1971;74(6):1003-1005

> *The traditionally accepted sequence has been that after heart–lung arrest, loss of consciousness first, and then BD [brain death] occurs. In the early 1950s, the advent of mechanical ventilators allowed for the artificial prolongation of cardiac and lung function and reversed the conventionally accepted chain of events to one initiated with death of the brain followed by heart and lung arrest.…Society has not had sufficient time to accept and change to a paradigm in which death does not follow the pattern of heart-beat arrest. Thus, brain death can only be blamed as being a relatively young artificial construct based on a counterintuitive concept. This does not imply that brain death is not a biological truth.*[16]

71. The authors' review of the literature also concludes, in respect of Islam, that '*Although brain death is accepted as true death by a majority of Muslim scholars and medical organizations, as evidenced by decisions from [various Muslim faith bodies], and other faith-based medical organizations, and the legal rulings by multiple nations, the consensus in the Muslim world is not unanimous, and there is a sizable minority that still accepts death by cardiopulmonary criteria only.*'

72. What would it mean in practice if religious perspectives were accommodated? What number of patients would be involved, and for how long would ventilation be likely to be continued before circulatory death occurred in any event (or physical signs of decomposition became evident, which might affect the views of relatives). (In *Principles of Medical Law*, Murray Earle refers to establishment of hospitals for the dead in Germany and Austria in the 18th century, '*to house corpses until decomposition had started*'[17]).

Does the medical guidance need to be updated? Should there be procedural guidance for court applications?

73. The 2015 RCPCH guidance about young babies itself states that there should be an evidence review in 5 years (April 2020), and it is presumably anticipated that the 2008

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[16] To live and let die: a brain death symposium at the Pontifical Academy of Science. Estol CJ, Int J Stroke. 2007 Aug; 2(3):227-9. Perhaps unsurprisingly, there does not appear to be a complete consensus within the Catholic Church – see for example Nguyen D,. *Pope John Paul II and the neurological standard for the determination of death: A critical analysis of his address to the Transplantation Society*, Linacre Q. 2017 May; 84(2): 155–186, raising the possibility that the separation of body and soul can only be said to have occurred once biological signs of death are present, and querying the lack of large scale trials of the methods for ascertaining brain stem death.

[17] Principles of Medical Law, Grubb et al, 22.15.

Code will also be updated at some stage. What should the court make of cases where people said to be brain stem dead have not died or decomposed with a short space of time? Does the clinical guidance need updating or clarifying to reflect cases like that of Jahi McMath, or even **Re M**, who was still being ventilated 4 months after brain stem death was confirmed with no reported signs of decomposition? Would it be beneficial for more comprehensive guidance to be produced, similar to the BMA guidance on withdrawal of CANH, with accompanying guidance for families?

74. The RCPCH guidance on withdrawing treatment should be updated to reflect the correct legal position and the role of the court.

75. We also suggest that there should be a careful checklist developed to enable a streamlined court process to take place, where there is a consensus of medical opinion as to the presence of brain stem death.