Neutral Citation Number: [2023] EWHC 2244 (Fam)

Case No: FD23P00419

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 12/09/2023

Before:

THE HONOURABLE MR JUSTICE MACDONALD

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Between :

St George's University Hospitals NHS Foundation Trust	**Applicant**
- and –	
Andy Casey [1] **Samantha Johnson [2]** **Christine Marie Casey [3]** **Joe Martin Casey [4]**	**Respondents**
-and-	
The Official Solicitor to the Senior Courts	**Advocate to the Court**

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Mr Abid Mahmood (instructed by **Bevan Brittan LLP**) for the **Applicant**
The First Respondent did not appear and was not represented
The Second Respondent did not appear and was not represented
Mr James Bogle and Mr Paul Diamond (instructed by Direct Access) for the **Third and Fourth Respondents**
Ms Emma Sutton KC (instructed by the Official Solicitor) as **Advocate to the Court**

Hearing date: 8 September 2023

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Approved Judgment

I direct that no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

MR JUSTICE MACDONALD

This judgment was delivered in private. The Judge has given permission for the publication of this version of the judgment, which has been anonymised in accordance with a Reporting Restriction Order that has been granted in this matter.

Mr Justice MacDonald:

INTRODUCTION

1. The court has before it a Part 8 claim dated 18 August 2023 issued by St George's University Hospital NHS Foundation Trust pursuant to the inherent jurisdiction of the High Court, in respect of Mr Andy Casey, born on 3 February 2003. That application seeks a declaration that Mr Casey died on 16 July 2023 at 11.51pm. The Trust is represented by Mr Abid Mahmood of counsel.

2. By order of Moor J dated 23 August 2023, Mr Casey was joined as the First Respondent to these proceedings and the Official Solicitor appointed as his litigation friend. The Official Solicitor submits that that order was of no effect in circumstances where she had not agreed to act as litigation friend. I accepted that submission for reasons I set out in detail below. However, for reasons I will also come to below, I invited the Official Solicitor to act as Advocate to the Court, which invitation she accepted. The Official Solicitor instructs Ms Emma Sutton of King's Counsel. Mr Casey's mother, Samantha Johnson, is the Second Respondent. For understandable reasons, she has not felt able to attend this hearing and is not represented. At the outset of the hearing, I joined Mr Casey's sister, Christine Marie Casey, and his brother, Joe Martin Casey, as Third and Fourth Respondents to the proceedings. I heard oral evidence from Christine Casey and the partner of Joe Casey, Macy Jo Phelan. The Third and Fourth Respondent are represented by Mr James Bogle and Mr Paul Diamond of Counsel.

3. Proceedings concerning Mr Casey began by way of an application made out of hours in the Court of Protection for an order permitting brain stem testing of Mr Casey. Following Peel J granting that order, and upon the completion of brain stem testing that indicated that Mr Casey had died, the application currently before the court was issued in the Family Division for a declaration that Mr Casey is dead, along with consequential declarations that it is lawful for doctors to withdraw ventilatory support. In the circumstances, these proceedings are governed by the CPR (see *Redcar & Cleveland Borough Council v PR)* [2019] EWHC 2800 (Fam)).

4. In addition to joining the Third and Fourth Respondents, the court dealt with a number of further preliminary issues at the outset of the hearing.

5. First, the court determined that it was appropriate to relax the terms of the Reporting Restriction Order (RRO) to permit the naming of Mr Casey and the identification of members of the family and to permit the naming of the Trust and the hospital. Both these steps were taken in circumstances where those details were already in the public domain as the result of coverage in the press. I was not prepared to relax the current restrictions on publishing the names of the treating clinicians involved in this case.

6. Second, and in circumstances where an issue had arisen as to the proper role of the Official Solicitor in this case in circumstances where the Official Solicitor declined to act as Mr Casey's litigation friend, I invited the Official Solicitor to act as Advocate to the Court. I determined that it was appropriate in this case to invite the Official Solicitor to do so in light of the submission of the Third and Fourth Respondent that the legal approach to the determination of applications of this nature has been changed by reason of recent appellate authority, where the Official Solicitor sought to make submissions on the proper application of the power in CPR r.21.6(1) to appoint a litigation friend in

cases of this nature and where the Official Solicitor sought to persuade the court that further guidance is required with respect to the procedure to be adopted in cases of this nature, in circumstances where she submits that a growing number of such applications are being brought before the courts.

7. Finally, as a preliminary issue, I dealt with an application by the Third and Fourth Respondents pursuant to Part 35 of the CPR for permission to instruct an expert Neurologist. For the reasons given in my case management ruling during the hearing, I declined to grant permission. In summary, I was satisfied that the instruction of an expert neurologist was not reasonably required to determine these proceedings for the purposes of CPR r.35.1 having regard to the nature and extent of the evidence already before the court and to the narrow issue that the court is required to determine in this matter.

8. In determining this matter, I have had the benefit of reading the hearing bundle, hearing evidence from Dr S, Consultant in Neurointensive care, from the Third Respondent, Christine Casey, and from the partner of the Fourth Respondent, Macy Jo Phelan. I have also benefitted from comprehensive and helpful written and oral submissions from counsel. Finally, a large number of Mr Casey's family members and his friends attended the hearing and sat in court during the course of evidence and submissions. They conducted themselves with conspicuous dignity during what must have been for them a difficult and distressing experience.

9. Given the nature and extent of the issues in this case, I reserved judgment for a short period. I now set out below my reasons for reaching the decision that I have.

BACKGROUND

10. The fact that the background to this matter can be stated shortly belies the great tragedy that has befallen Mr Casey and, by extension, his family and friends.

11. On 9 July 2023, Mr Casey was on a night out when he was assaulted in a pub garden. Mr Casey was punched to the right side of his head and fell to the ground, suffering a catastrophic injury to his brain. Prior to the assault, Mr Casey was a healthy young man. Mr Casey was conveyed by the London Ambulance Service to St George's Hospital where, from the point of admission, his Glasgow Coma Scale was 3, indicating that he was in the deepest form of coma. A CT scan of Mr Casey's head showed widespread bleeding in and around his brain, comprising significant subarachnoid haemorrhage and intraventricular haemorrhage in both lateral ventricles, globally increased intracranial pressure, and possible early signs of hypoxic–ischaemic brain injury.

12. Mr Casey was admitted to the Neurointensive Care Unit for further assessment and management. Organ support, including invasive mechanical ventilation, was continued. He remained in the deepest form of coma, with unreactive pupils. Some spontaneous respiratory activity initially continued but this ceased on 13 July 2023. Four days after his admission to hospital, on 13 July 2023, Mr Casey's treating clinicians suspected that his brain stem had died, given the absence of any brain stem reflexes. The need for brain stem testing was discussed with Mr Casey's family, who were unable to consent to that course.

13. In circumstances where there was a narrow window for brain stem testing to be undertaken safely, an application was made out of hours to Peel J sitting as a judge of the Court of Protection on 16 July 2023. Peel J made an order permitting brain stem testing. The court has the benefit of counsel's note of Peel J's *ex tempore* judgment. Peel J determined that brain stem testing was in Mr Casey's best interests. Pursuant to the order of Peel J authorising brain stem testing, the Trust proceeded to administer testing to Mr Casey in accordance with the 2008 Code of Practice for the Diagnosis and Confirmation of Death by the Academy of Medical Royal Colleges (hereafter 'the 2008 Code of Practice').

14. Section 6 of the 2008 Code of Practice requires two appropriately qualified doctors to be satisfied of the following factors as demonstrating the clinical criteria of death resulting from irreversible cessation of brain stem function, which factors demonstrate the permanent absence of consciousness and thus the ability to feel or do anything:

    i) The absence of brain stem reflexes;

    ii) That pupils are fixed and do not respond to sharp changes in the intensity of incident light;

    iii) That there is no corneal reflex;

    iv) That the oculo-vestibular reflexes are absent, demonstrated by no eye movements being observed during or following the slow injection of at least 50mls of ice-cold water over one minute into each external auditory meatus in turn;

    v) That there are no motor responses within the cranial nerve distribution elicited by adequate stimulation of any somatic area;

    vi) That there is no cough reflex in response to bronchial stimulation by a suction catheter placed down the trachea to the carina, or gag response to stimulation of the posterior pharynx with a spatula.

    vii) That there is no respiratory response to hypercarbia (apnoea test), which test should not be performed if any of the preceding tests confirm the presence of brain stem reflexes.

15. The 2008 Code of Practice requires that the diagnosis of death by brain stem testing should be made by at least two medical practitioners who have been registered for more than five years and are competent in the conduct and interpretation of brain stem testing. At least one of the doctors must be a consultant. In his second statement, Dr S states that the first five tests stipulated by the 2008 Code of Practice have been undertaken on a periodic basis throughout Mr Casey's hospital admission. He further states that since 13 July 2023, there has been no positive response to these tests.

16. The full spectrum of tests stipulated by the 2008 Code of Practice was carried out by Dr O, Consultant Neurointensivist, and Dr C, Consultant Neurointensivist, on 16 and 17 July 2023. The court has a statement from Dr C, which evidence was not challenged. Prior to the testing, and in accordance with the 2008 Code of Practice, Drs C and O satisfied themselves that Mr Casey's condition was due to irreversible brain damage

caused by the combination of a traumatic brain injury and hypoxic–ischaemic encephalopathy. They excluded reversible causes of coma and apnoea, including dependence on drugs, hypothermia, and circulatory, metabolic and endocrine disturbances. They further satisfied themselves that it was not likely that there was a cervical cord injury causing apnoea, noting that spontaneous breathing activity had been present prior to the loss of brain stem reflexes, indicating intact neural pathways controlling ventilation at that stage. In addition, they ensured that Mr Casey's mean arterial blood pressure was consistently above 60 mmHg. Dr O examined both ears using an otoscope and confirmed there was a clear view of both tympanic membranes. Residual neuromuscular blockade was ruled out using a peripheral nerve stimulator.

17. The seven tests stipulated by the 2008 Code of Practice were then performed on Mr Casey. The tests were performed at 11.51pm on 16 July 2023 by Dr O, with Dr C observing, and again at 12.17am on 17 July 2023 by Dr C, Consultant with Dr O observing. Both sets of tests were observed by some members of Mr Casey's family, including his mother.

18. The testing satisfied both Dr C and Dr O that there was no response of brain stem activity from Mr Casey on either occasion. In these circumstances, the doctors agreed that death was diagnosed by the first, diagnostic, set of tests at 23:51 on 16 July 2023, and confirmed on completion of the second, confirmatory, set of tests at 00:37 on 17 July 2023. Time of death for Mr Casey was recorded as 23.51 on 16 July 2023.

19. In performing the tests, the doctors used the Short Form version of the Form for Diagnosis of Death using Neurological Criteria. In his second statement, Dr S explained that the terms 'short' and 'long' in this context refer to the documents used to record the tests, not to the tests themselves. Dr S told the court that the 'long' form is intended for clinicians who do not perform brain stem tests frequently, in order to guide them through what may be a relatively unfamiliar process. By contrast, the 'short' form requires that the same tests stipulated by the 2008 Code of Practice be performed, and the same preconditions met, but permits the outcome to be recorded on a shortened document. Both formats are approved. In this context, Dr S stated that in circumstances where St George's Neurointensive Care Unit is a high-volume centre staffed by clinicians who are very familiar with the tests and perform them frequently, it is standard practice on the unit to use the short form.

20. Following brain stem testing that indicates brain stem death, the withdrawal of organ support would usually follow within 24 hours thereafter and, only exceptionally, after 48 hours. However, the family was unable to accept the results of the tests. I acknowledge that it is said on behalf of the family that, in the context of their religious and philosophical beliefs, they disagree that brain stem death is the same as death in the ordinary sense of the word and have expressed doubt about the validity of brain stem testing as a methodology. However, it is clear that the genesis of the family's concerns centred on what they were witnessing when visiting Mr Casey, matters that Christine Casey, Joe Casey and Macy Jo Phelan sought to emphasise both in their written and, in the case of Christine Casey and Macy Jo Phelan, their oral evidence.

21. Each family member who gave evidence stated that they had seen movements from Mr Casey that they consider indicate that he is not brain stem dead. Further, they contend that Mr Casey has initiated breaths spontaneously. In her statement to the court, Christine Casey states as follows:

> "6. I have observed the following. Andy is moving his hands and fingers, he is also moving his head from side to side and I have seen him do so at least 15 times in a day during my visits.
>
> 7. On verbal request from me or other members of the family, Andy will move his head, hands and/or fingers.
>
> 8. On verbal request from me or other members of the family, Andy will squeeze my fingers and those of other members of the family, particularly Joe and Macy Jo. He also, when his hand is lifted up, pushes back down on my hand and I have seen him do the same with other members of the family rather like light arm-wrestling.
>
> 9. I have observed Andy doing these movements forcefully and strongly often for between 5 and 10 seconds at a time and the movements very clearly appear deliberate and not as jerks or spasms.
>
> 10. I have also observed Andy triggering the breathing machine on numerous occasions which, I am told by Dr D, means that Andy is breathing on his own initiative not simply forced by the machine. When this occurs, a symbol represented by two lungs, appears on the face of the machine and, in addition, the measured resting rate of breathing increases above the level to which it is set.
>
> 11. The family has taken videos of Andy and they demonstrate what I have described above. These videos will be provided to the court and the Claimant."

22. The statement of Joe Casey describes events of this nature in similar terms. In their statements, both Christine Casey and Joe Casey further state that they observed an occasion, on 29 July 2023, when the ventilator was removed from Mr Casey and he continued to breathe independently for half a minute, unaided. In her statement, Macy Jo Phelan also relates the movements she has seen Mr Casey make and comments as follows in respect of breathing:

> "I have also observed Andy triggering the breathing machine on numerous occasions which, I am told by Dr D, means that Andy is breathing on his own initiative not simply forced by the machine. When this occurs, a symbol represented by two lungs, on the face of the machine and, in addition, the measured resting rate of breathing increases above the level to which it is set. I was also informed by one of the nurses that this is how the machine works."

23. In circumstances I shall come to, the family has been permitted by the hospital to film the events described in the foregoing paragraphs. Copies of those videos, some thirty six in number, and a still image, have been provided to the court and I have carefully considered them. As I shall come to, whilst disputing the contention that Mr Casey has, at any point, initiated a breath, the Trust does not dispute, in broad terms, the descriptions provided by the family of the movements exhibited by Mr Casey.

24. In light of the inability to agree a way forward with the family, and at the request of the family, a meeting of the hospital's Ethics Committee took place on 26 July 2023. The

court has the benefit of the minutes of that meeting. The Ethics Committee agreed unanimously with the clinical decision-making and the intention to discontinue Mr Casey's organ support. The conclusion of the Ethics Committee was that there was no ethical decision to be made *per se*, although the fundamental difference in models of belief between the clinicians and the stated beliefs of the family regarding brain stem death and its implications was acknowledged. The Ethics Committee further recognised that international differences exist in the diagnosis of death but, in circumstances where Mr Casey is brain stem dead, considered that there was, both ethically and legally, no further purpose to be served by continuing organ-sustaining treatment, which should be withdrawn. A mediation took place between the Trust and the family on 27 July 2023. Mr Casey's family was represented by leading and junior counsel. The mediation did not resolve matters.

25. During this period, Mr Casey's family sought the views of Dr Christopher Danbury, a Consultant in Intensive Care Medicine well known to this court. Dr Danbury did not, it would appear, produce a written report, but his views were communicated via lawyers acting for the family by way of further representations to the hospital Ethics Committee. Dr Danbury's views are set out in the second statement of Dr S.

26. Dr Danbury considered it would have been preferable to use the 'long' form version of the Form for Diagnosis of Death using Neurological Criteria, as this requires the clinician to go through the long preamble to ensure red flags like a C1 injury are recognised. Dr Danbury considered that a C1 fracture sustained by Mr Casey was relevant as, although it was likely to be stable, the presence of such a fracture meant that ligamentous injury could not be exclude by CT and that, therefore, cervical spinal cord injury needed to be confirmed or refuted by an MRI of the cervical spinal cord. Within this context, Dr Danbury strongly recommended performing a repeat CT, a CT angiography and an MRI scan of brain, brain stem and cervical spine. He considered an EEG would be useful but needed to be taken in context with MRI. Dr Danbury further considered that whilst hand squeezing could be attributed to spinal reflexes, head movements might be of potential significance, and depending on the source of the movement, could invalidate a diagnosis of brain stem death, but to determine this he would need to witness these movements first hand or by video evidence. He therefore considered that the family should be permitted to video Mr Casey's movements. Finally, Dr Danbury stated that he would have placed Mr Casey in a cervical collar in circumstances where ligamentous injury to the high cervical spine could not be excluded. Dr Danbury considered that the performance of these additional tests would ensure that Mr Casey's family could be confident of the nature of the severity of the injury and likely prognosis of Mr Casey's condition.

27. In parallel, the Trust also sought second opinions from internal neurosurgical specialists, Dr A and Dr B, in respect of Mr Casey's spinal injury and an external expert with expertise in the diagnosis of death by neurological criteria, Dr E. Dr A and Dr B considered that the minor fracture sustained by Mr Casey was not relevant to the diagnosis of death, although the court has only a clinical record recording this opinion. Dr E provided the clinical team with a national perspective on the clinical criteria and, more particularly, advice on the role of ancillary investigations in support of a diagnosis.

28. Whilst not considering them necessary in light of the outcome of the brain stem testing results undertaken on 16 July 2023 in accordance with the 2008 Code of Practice, and

whilst disagreeing with a number of the assertions and recommendations made by Dr Danbury, Dr S stated that the clinical team recognised that Dr Danbury had similar qualifications to that team. The Ethics Committee recognised that an MRI of the brain would be potentially valuable as it would show the global extent of Mr Casey's head injury and the hypoxic damage to the brain stem, although it would not itself confirm or refute the diagnosis of death. Within this context, and to seek to ensure the family had the fullest confidence in the clinical assessment, an MRI of Mr Casey's brain and spinal cord was undertaken on 31 July 2023.

29. The MRI scan of Mr Casey's brain and spinal cord revealed devastating changes in the brain consistent with the known insult suffered by Mr Casey (which comprised the initial hypoxic–ischaemic injury caused by his cardiac arrest and the secondary ischaemic injury caused by brain swelling and elevated intracranial pressure); distortion of brain tissue consistent with 'coning' (i.e. part of the cerebellum had herniated through the foramen magnum and now sat adjacent to the upper cervical cord) leading to compression and irreversible ischaemic injury of the brain stem, with the resulting irreversible loss of the capacity for consciousness and breathing, and to extensive damage to Mr Casey's spinal cord; no evidence of a traumatic spinal injury other than the known fracture Mr Casey's C1 transverse process; no ligamentous injury that could have given rise to a spinal cord injury capable of confounding the brain stem tests; and the loss of normal flow voids in the internal carotid and vertebral arteries (the four vessels that, collectively, supply blood to the brain) implying that Mr Casey's brain is no longer receiving a blood supply, a state incompatible with brain function. The scan was considered by treating clinicians to be supportive of the diagnosis of death reached as a result of the brain stem testing performed on 16 July 2023.

30. The family sought further tests. The clinical team was convinced that ancillary testing was not necessary, but again sensitive to the family's need to understand Mr Casey's condition and hoping to resolve matters by way of agreement rather than an application to the court, two further tests were carried out as requested by the family. Namely, a CT angiography on 1 August 2023 and an EEG on 2 August 2023.

31. The CT angiography (CTA) of Mr Casey's intercranial vessels showed evidence of extremely elevated intracranial pressure with complete disseminated intra-arterial thrombosis of the anterior and posterior circulation and absolutely no contrast delivery to the intradural circulation. Dr S stated that the hyperdensity in the terminal portion of both internal carotid arteries, and all the visualised branches of these within the skull, indicated that thrombus (i.e. blood clot) had filled the large arteries supplying the brain, such that there was no longer a means for blood to be delivered to Mr Casey's brain. Dr S stated that this is an expected effect of the devastating global brain injury sustained by Mr Casey. He considered it a state incompatible with life and as unequivocally consistent with brain stem death. As with the MRI undertaken on 31 July 2023, the CTA performed on 1 August 2023 was considered supportive of the diagnosis of death reached as a result of the brain stem testing performed on 16 July 2023.

32. The electroencephalography (EEG) performed on 2 August showed changes expected after death, with no discernible bioelectrical brain rhythms, and no changes during external stimulation. Reactivity was tested by calling Mr Casey's name, undertaking passive eye opening/ closing the eyelids, clapping, bilateral alternating trapezius squeeze and suction performed by a nurse. These actions did not lead to any changes

on the EEG. The clinical team considered that these results were again consistent with the clinical diagnosis of death.

33. During his evidence, Dr S described the level of testing of Mr Casey above and beyond the brain stem testing undertaken on 16 July 2023 in accordance with the 2008 guidelines as being highly exceptional. He noted further that as against the standard 24 to 48 hours of clinical observations undertaken following brain stem testing indicating brain stem death, Mr Casey has had eight weeks of intensive clinical observations. With respect to the provenance of the highly exceptional levels of testing undertaken on Mr Casey in the context of the ongoing movements witnessed in Mr Casey by the family, in his statement Dr S states as follows, which was not the subject of significant challenge:

> "[25] Neuroanatomically, it is not possible for the movements that the family observe to be voluntary. The clinical tests to diagnose death have established that there has been irreversible loss of the capacity for consciousness. A study of the blood flow to the brain (a CTA scan) demonstrates complete absence of blood flow to the brain, which is incompatible with function that could generate voluntary movements. The MR scan of the brain is also supportive, and in addition, the MR scan of the cervical spine shows that following the herniation of hindbrain structures into the spinal canal, the upper cervical cord is severely damaged. This means that even if there were to be residual brain activity, there is no functional pathway for signals to be transmitted to the limbs.
>
> [26] Neurophysiologically, the ability of AC's brain to receive and process verbal and auditory stimuli has been assessed by EEG on calling his name and clapping. This, and all other forms of stimulation (passive eye opening and closing, painful stimulation, deep chest suctioning), did not lead to any changes on the EEG – in other words, the EEG provided no evidence that the brain was reactive to external stimulation.
>
> [27] Even if the extensive clinical, anatomical, blood flow and electrophysiological evidence of death is disregarded, the suggestion that AC has regained the capacity to respond meaningfully to verbal stimuli, while other simpler responses and reflexes remain absent, is clinically and scientifically implausible. Processing language, and generating a motor response to this verbal stimulus, requires intact sensory pathways, intact higher processing, and intact motor pathways (which pass through the brain stem). If such pathways and functions were intact (as this interpretation requires, but which, for the avoidance of doubt, we know not to be the case), it is implausible that there would not also be a response to painful stimulation. Indeed, responses to painful stimulation would invariably precede the recovery of the capacity to respond to verbal instruction. Furthermore, if brain stem function were sufficiently intact to facilitate sensory and motor transmission (which again is required to support this interpretation, but which we know not to be the case), then both biologically and clinically, basic brain stem reflexes (such as AC's pupils reacting to light, eyelid movement when the AC's cornea's are touched, motor responses when supraorbital pressure is applied, gag reflex, cough reflex and any eye movement during or

> following caloric testing in each ear) would also be expected to be present – but all remain absent.
>
> [28] It is therefore on the basis of the totality of evidence – clinical, anatomical, blood flow, electrophysiological, scientific rationale, and published evidence on the prevalence of brain-death associated movements – that we can say with such confidence that the movements cannot be emerging from, or mediated by, his brain."

34. With respect to the provenance of the highly exceptional levels of testing undertaken on Mr Casey in the context of the spontaneous breaths stated to have been witnessed by the family, in his statement Dr S states as follows, which evidence was again not the subject of significant challenge:

> "[32] As with the movements discussed above, it is not neuroanatomically possible for AC to exhibit spontaneous breathing. The clinical tests to diagnose death have established that there has been irreversible loss of the capacity to breathe. The CTA demonstrates complete absence of blood flow to the brain, which is incompatible with function in the respiratory centres of the brain stem which could initiate breathing. The MR scan of the brain is supportive of this, showing devastating brain injury and an absence of flow voids in the intracranial arteries. The MR scan of the cervical spine shows that following the herniation of hindbrain structures into the spinal canal, the upper cervical cord is severely damaged (all reports are provided as exhibits to my first witness statement). This means that even if there were to be residual brain activity, there is no functional pathway for signals to be transmitted to the chest (the fibres controlling the diaphragm and chest muscles exit the cord at the level of C3 and below, and this section of the cord is essentially disconnected from the brain by the damage above it)."

35. A very high input of nursing and clinical intervention continues to be provided to Mr Casey despite the confirmation of brain stem death obtained on 16 July 2023 by application of the 2008 Code of Practice. In circumstances where an impasse has been reached with respect to withdrawal of organ sustaining intervention on Mr Casey, this application is made to the High Court for a declaration in the following terms:

    i) Andrew Casey died at 23.51 hours on 16 July 2023 when irreversible cessation of brain stem function had been conclusively established, he having lost the essential characteristics necessary to the existence of a living human person namely (a) the irreversible loss of the capacity for consciousness (i.e. a permanent absence of consciousness), along with (b) the irreversible loss of capacity to breathe, thus the inevitable and rapid deterioration of integrated biological function.

    ii) In the circumstances, it is lawful for a consultant or other medical professional at the hospital part of the St George's University Hospitals NHS Foundation Trust to (a) cease to mechanically ventilate and/or to support the respiration of Andrew Casey, (b) to extubate Andrew Casey, (c) cease the administration of medication to Andrew Casey and (d) not attempt any cardio or pulmonary resuscitation upon Andrew Casey when respiration and cardiac output ceases.

THE LAW

36. As I have intimated above, the court heard argument in this case as to the correct procedural and legal approach to applications of this nature. Having considered carefully those submissions, I am satisfied that the following represents the now well established legal and procedural position with respect to applications in the Family Division under the inherent jurisdiction for a declaration of death in respect of an adult.

37. For many centuries, the question of whether someone had died was considered to be a relatively straightforward one. In the modern world, however, with its increasingly sophisticated medical treatments and in circumstances where death is now recognised as a process rather than an event, the question of whether someone has died can be one of some difficulty. Against this, as recognised in the 2008 Code of Practice:

> "Whilst dying is a process rather than an event, a definition of when the process reaches the point (death) at which a living human being ceases to exist is necessary to allow the confirmation of death without an unnecessary and potentially distressing delay."

38. There is no statutory definition of death in this jurisdiction. In 1976 the Conference of Medical Royal Colleges proposed criteria for brain death based on the absence of brain stem reflexes. In *Airedale NHS v Bland* [1993] AC 789, the House of Lords accepted the validity of a medical diagnosis of death arising from an irreversible absence of brain stem function. In *Airedale NHS v Bland* Lord Keith stated as follows at 856:

> "In the eyes of the medical world and of the law a person is not clinically dead so long as the brain stem retains its function."

Lord Gough observed at 863 that:

> "I start with the simple fact that, in law, Anthony is still alive. It is true that his condition is such that it can be described as a living death; but he is nevertheless still alive. This is because, as a result of developments in modern medical technology, doctors no longer associate death exclusively with breathing and heart beat, and it has come to be accepted that death occurs when the brain, and in particular the brain stem, has been destroyed: see Professor Ian Kennedy's paper entitled "Switching off Life Support Machines: The Legal Implications," reprinted in Treat Me Right, Essays in Medical Law and Ethics, (1988), especially at pp. 351-352, and the material there cited. There has been no dispute on this point in the present case, and it is unnecessary for me to consider it further. The evidence is that Anthony's brain stem is still alive and functioning and it follows that, in the present state of medical science, he is still alive and should be so regarded as a matter of law."

Finally, at 873 Lord Brown-Wilkinson stated as follows (emphasis added):

> "I have no doubt that it is for Parliament, not the courts, to decide the broader issues which this case raises. Until recently there was no doubt what was life and what was death. A man was dead if he stopped breathing and his heart stopped beating. There was no artificial means of sustaining these indications

> of life for more than a short while. Death in the traditional sense was beyond human control. Apart from cases of unlawful homicide, death occurred automatically in the course of nature when the natural functions of the body failed to sustain the lungs and the heart.
>
> Recent developments in medical science have fundamentally affected these previous certainties. In medicine, the cessation of breathing or of heartbeat is no longer death. 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."”

39. The rationale for the absence of brain stem reflexes being the criteria for brain death is set out in Appendix 5 of the 2008 Code of Practice:

> “The brain stem controls all the essential functions that keep us alive, most importantly our consciousness/awareness, our ability to breathe and the regulation of our heart and blood pressure. Once the brain stem has died it cannot recover and no treatment can reverse this. Inevitably the heart will stop beating; even if breathing is supported by a machine (ventilator)”

40. Within the foregoing context, Section 2 of the 2008 Code of Practice provides a definition of death as follows:

> “Death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person and, thus, the definition of death should be regarded as the irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe. This may be secondary to a wide range of underlying problems in the body, for example, cardiac arrest.”

And in this context defines the characteristics of a diagnosis of death in the following terms:

> “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.”

41. As set out above, the 2008 Code of Practice stipulates the clinical tests that are to be administered, and which were administered in this case, to establish whether a diagnosis of death can be made and confirmed. Section 4 of the 2008 Code of Practice provides as follows with respect to the actions to be taken where death is diagnosed and confirmed as the result of the administration of those tests:

> "When death has been diagnosed by the methods to be described, the patient is dead even though respiration and circulation can be artificially maintained successfully for a limited period of time. The appropriate course of action is then to consider withdrawal of mechanical respiratory support, the ethical justification for which has passed, and to allow the heart to stop. This imposes an unnecessary and distressing vigil on the relatives, partners and carers, who should be kept fully informed by the local care team of the diagnosis, the inevitable outcome and the likely sequence of events."

42. It follows from the matters set out above that, where there is a dispute about whether a person has died, until brain stem testing has been administered in accordance with the 2008 Guidelines and indicated a cessation of brain stem function, it is not possible to say, in law, that the person is dead.

43. Where a dispute arises as to whether brain stem testing should be *administered* on an individual whom it is said has died, it is clear that, in circumstances where a person about whom there is a question of whether or not they are dead will inevitably lack capacity, the issue of whether brain stem testing should take place falls to be decided in the Court of Protection. That decision will be taken in accordance with the cardinal principles set out in the Mental Capacity Act 2005, namely and in short terms, whether such test in the best interests of the person lacking capacity.

44. Once brain stem testing has been administered, however, and where that test has indicated that a person has died by reference to the criteria set out in the 2008 Code of Practice, if that outcome is the subject of a dispute the case becomes one to be decided in the Family Division under the inherent jurisdiction of the High Court. Where the case concerns an adult, the procedural aspects of the case will be governed by the CPR per the decision of Cobb J in *Redcar & Cleveland Borough Council v PR* noted above. The approach of the court to determining such applications is, I am satisfied, governed by the following principles.

45. In *Re A (A Child)* [2015] EWHC 443 (Fam); [2016] 1 FLR 241, Hayden J was concerned with a child who had been declared dead following the completion of two brain stem tests carried out in accordance with what Hayden J characterised as "well established guidelines". In circumstances where the case involved a child, Hayden J considered both the 2008 Code of Practice as it applies to infants and the recommendations of the 1991 "Report of a working party of the British Paediatric Association on the diagnosis of brain stem death in infants and children". By reference to the 2008 Code of Practice, Hayden J concluded on the evidence that the child had died. Whilst Hayden J was thereafter required to consider an issue that had arisen in the case regarding the role of the Coroner in cases of the type he was dealing with, that issue did not bear on the approach Hayden J took to determining whether the child had died. The approach taken by Hayden J to that issue, namely to determine whether the criteria for brain stem death set out in the 2008 Code of Practice are established on the evidence before the court, was also adopted by Francis J in *Oxford University NHS Trust v AB and others* [2019] EWHC 3516 (Fam), also a case involving the death of a child.

46. The approach taken by Hayden J in *Re A*, and followed by Francis J in *Oxford University NHS Trust v AB and others*, was expressly endorsed by the Court of Appeal in *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164; [2020] 4 WLR 52.

That appeal was from a decision of Lieven J, who had determined that declarations should be granted in respect of an infant who had been declared dead following two brain stem tests. In circumstances where House of Lords authority determined that brain stem death was the correct legal criteria for death to be applied in the United Kingdom, where it was not possible in those circumstances for the Court of Appeal to embark upon an assessment of whether a different test, used in other jurisdictions, ought to replace the long established UK criteria represented in the authoritative medical codes of practice and where the factual and medical evidence before the judge was more than sufficient to justify her findings, permission to appeal was refused by the Court of Appeal.

47. In refusing permission to appeal, the President of the Family Division held that Lieven J had correctly identified the issue to be determined by the court as whether the child was dead according to the outcome of the brain stem tests and the relevant clinical guidance. In the circumstances, the President further made clear as follows at [24]:

> "[24] In contrast to issues concerning the medical treatment of the living, whether they be children or adults who lack capacity, where the best interests of the individual will determine the outcome, where a person is dead, the question of best interests is, tragically, no longer relevant."

48. In this context, the President commended the judgment of Hayden J in *Re A* as setting out the correct structure for dealing with applications of this nature. The President further endorsed the terms of the declarations made by Hayden J. Namely, a declaration that the child had died at a specific time on a specific date by reason of having lost the essential characteristics necessary to the existence of a living human person namely (i) the irreversible loss of the capacity for consciousness (i e a permanent absence of consciousness), along with the (ii) irreversible loss of the capacity to breathe; thus the inevitable and rapid deterioration of integrated biological function, and a declaration permitting the withdrawal of medical intervention as being lawful.

49. Whilst the authorities set out above concerned children rather than adults, I am satisfied that the same principles applied by the Court of Appeal in *Re M* apply in this case. I am reinforced in this conclusion by the decision of Sir Jonathan Cohen in *North West Anglia NHS Foundation Trust v BN & PS* [2022] EWHC 663 (Fam), in which the learned Judge, adopting the structure set out in *Re A* and endorsed by the Court of Appeal in *Re M (Declaration of Death of Child)*, declared a women in her forties, who had been declared dead following the administration of brain stem testing, to be dead having been satisfied that that was the outcome of brain stem testing and the application of the 2008 Code of Practice. Sir Jonathan Cohen further permitted the removal of medical intervention as being lawful.

50. In the foregoing circumstances, the clearly settled position under the law is that once a court is satisfied on the balance of probabilities that, on the proper application of the 2008 Code of Practice, brain stem death has occurred, there is no basis for a best interests analysis, nor is one appropriate or legally relevant. Further, once the court is satisfied on the balance of probabilities that, on the proper application of the 2008 Code of Practice, brain stem death has occurred, the task of the court, where a dispute arises, is to confirm that the subject of the application is dead, declare that he or she died at a particular time on a particular date and declare, accordingly, that the withdrawal of medical intervention is lawful.

51. On behalf of the Third and Fourth Respondent, Mr Bogle and Mr Diamond sought to persuade the court that the decision of the Court of Appeal in *Barts NHS Trust v Dance* [2022] EWCA Civ 935, [2022] 4 WLR 83, [2023] 1 FLR 731 has changed the approach set out above to applications for a declaration of death. In particular, Mr Bogle and Mr Diamond submit that the consequence of the decision of the Court of Appeal in *Barts NHS Trust v Dance* is that the question of whether to grant a declaration of death under the inherent jurisdiction is one that, as with the decision whether to carry out such a test, falls to be taken based on the subject's best interests. I cannot accept that submission.

52. In *Barts NHS Trust v Dance* the Court of Appeal was dealing with a case in which it was not possible to conduct a brain stem test in accordance with the 2008 Code of Practice and where, therefore, no medical witness had diagnosed death in accordance with the 2008 Code of Practice. In such circumstances, the Court of Appeal held that the appropriate course was to proceed to a best interests assessment as soon as it became apparent that brain stem testing was not possible. In these circumstances, I am not able to accept that the decision in *Barts NHS Trust v Dance* is authority for the proposition that where death has been diagnosed by reference to the 2008 Code of Practice, as it has in this case, any dispute in respect of the diagnosis falls to be determined on the basis of the subject's best interests. The decision of the Court of Appeal in *Re M (Declaration of Death of Child)* demonstrates that that proposition is plainly not correct.

53. With respect to procedure, following the issue of proceedings, on 23 August 2023 Moor J made the following order with respect to the party status of Mr Casey:

> "2. [Mr Casey] is joined as a party to these proceedings and the Official Solicitor is appointed to act as litigation friend on behalf of [Mr Casey], but if the Official Solicitor takes the view that she does not seek to be a part of these proceedings then permission is granted for a Position Statement to be filed and served by her setting out any reasons and her further attendance from this hearing shall be excused and the appointment as litigation friend terminated. Such Position Statement shall be filed and served by 4pm on 5th September 2023."

54. The Official Solicitor submits that, absent her prior agreement to act as Mr Casey's litigation friend having been obtained, paragraph 2 of the order of Moor J appointing her as Mr Casey's litigation friend was of no effect, CPR rule 21.6(2)(b) providing that an application may be made for an order appointing a litigation friend by a person who "wishes" to act as litigation friend (the term "consent" is used in the FPR 2010 r. 15.6(1)(b)) and COPR 2017 rr. 17.4(1)(a) and 17.4(2)(b)). The Official Solicitor submits that as she did not "wish" to be appointed as Mr Casey's litigation friend the order of Moor J of 23 August 2023 can be of no effect and an order terminating her appointment pursuant to CPR r. 21.7(1)(b)) is not therefore necessary.

55. The submission that CPR r.21.6(1) requires the agreement of the Official Solicitor before the court can appoint her as a litigation friend under that provision would appear to be correct. As nothing in CPR r.21.6(1) provides otherwise, the court may exercise its powers under that rule of its own motion pursuant to CPR r. 3.3(1). However, whilst I did not hear detailed submissions on the point, as noted in the White Book by its terms r.21.6(1) envisages the powers conferred by that rule exercised on application by the persons referred to in r.21.6(2), namely a person who wishes to be the litigation friend.

This lends support the position of the Official Solicitor that, absent her agreement, the court cannot appoint her as a litigation friend of its own volition in proceedings of this nature.

56. The Official Solicitor further submits that, in contradistinction to proceedings in the Court of Protection in which the issue is whether brain stem testing should be undertaken, it is not ordinarily necessary to join as a party to proceedings an adult who has been declared dead following testing having been completed in accordance with the 2008 Code of Practice, given the narrow question that falls to be determined where there is a dispute.

57. There is no procedural rule that requires the person who has been declared dead by reference to the 2008 Code of Practice to be joined as a party where a dispute arises. This is consistent with the narrow nature of any proceedings that follow on from that outcome as confirmed by the Court of Appeal in *Re M (Declaration of Death of Child)*. The proceedings following brain stem testing diagnosing and confirming brain stem death are not concerned with any best interests decision, but rather the narrow question of whether the subject of the application is dead according to the outcome of those brain stem tests and the 2008 Code of Practice. This requires the court to consider the results of the brain stem testing undertaken and ascertain whether the tests were undertaken in accordance with the 2008 Code of Practice. Within this context, and in circumstances where there is no best interests decision in respect of which the Official Solicitor can discharge her duties (or, in the case of a child, the Children's Guardian), I note that in *North West Anglia NHS Foundation Trust v BN & PS*, a case in which the application of the 2008 Guidelines had established that the adult subject of that application was brain stem dead, that adult was not made a party to the proceedings. Likewise, in *Re A (A Child)* and in *Oxford University NHS Trust v AB*, the subject children were not parties to the proceedings represented by a Children's Guardian.

58. Again, Mr Bogle and Mr Diamond submitted that the decision in *Barts NHS Trust v Dance* has changed the approach taken in the cases cited in the foregoing paragraph. In submitting that the Official Solicitor should take on the role of litigation friend to an adult subject of the application for a declaration of death, Mr Bogle and Mr Diamond rely on the following passages from the judgment of the Court of Appeal in *Barts NHS Trust v Dance*:

> "[43] Whilst understanding the difficult professional position that the Guardian was placed in, having herself concluded that Archie was "dead beyond doubt", it was, ultimately, for the court to determine whether or not to make a declaration of death. At all stages prior to a declaration of death being made, Archie remained a party to the proceedings and his children's guardian retained the duties placed upon her by [7.6] and [7.7] of PD16A of the Family Procedure Rules 2010 . As a CAFCASS officer, the Guardian was, in addition, subject to the duties contained in Part 3 of PD16A, which include a requirement at [6.6(e)] to advise the court on "the options available to [the court] with respect to the child and the suitability of each such option including what order should be made in determining the application". Unless the court otherwise directs, the children's guardian must "file a written report advising on the interests of the child" ([6.8(a)] of PD 16A).

> [44] In future cases, even where a children's guardian apprehends that the medical evidence may establish that the represented child has died, the guardian should discharge their continuing duty to advise the court on best interests unless and until a declaration of death has been made."

59. Once again, I am satisfied that the decision in *Barts NHS Trust v Dance* cannot bear the weight that Mr Bogle and Mr Diamond seek to place on it. Once again, it must be remembered that in *Barts NHS Trust v Dance* the Court of Appeal was dealing with a case in which it was not possible to undertake brain stem testing in accordance with the 2008 Guidelines. In the circumstances, the case remained one in which there had been no declaration of death as a result of the application of the 2008 Code of Practice and, hence, one in which there remained a best interests decision to be taken. Once again where, as in this case, brain stem testing has been undertaken in accordance with the 2008 Code of Practice, as made clear in *Re M (Declaration of Death of Child)* there is no longer any best interests decision to be made, the court being concerned only with the question of whether the subject of the application is dead, requiring the court to consider the results of the brain stem testing undertaken and ascertain whether the tests were undertaken in accordance with the 2008 Code of Practice.

60. In the foregoing context, and as I indicated at the outset of the hearing, I am satisfied that the order of 23 August 2023 did not operate to appoint the Official Solicitor as litigation friend for Mr Casey. I am further satisfied in any event, that it was not necessary to join Mr Casey as a party to the proceedings in the circumstances I have set out above. In circumstances where Mr Casey was joined as a party to the proceedings however, notwithstanding the order appointing the Official Solicitor as his litigation friend was of no effect, pursuant to CPR r.21.3(4) any step taken by the court can have no effect unless the court orders otherwise.

61. Finally with respect to the law and procedure, on behalf of the Official Solicitor, Ms Sutton invites the court to give guidance as to the correct approach to applications under the inherent jurisdiction for declarations of death in respect of adults, which the Official Solicitor submits are becoming more prevalent. I am reluctant to give general guidance in circumstance where the court is dealing with a single case that falls to be determined on its own facts. However, I am able to summarise the conclusions that I am satisfied can be drawn from the survey of the relevant law and procedure set out above:

    i) It is for doctors to diagnose and confirm death by brain stem testing carried out in accordance with the 2008 Code of Practice. In the circumstances, applications to the court concerning diagnosis and confirmation of death should be the exception.

    ii) Where there is a dispute about whether brain stem testing should be performed in respect of an adult who it is suspected has died, an application should be made to the Court of Protection. The question of whether brain stem testing should be undertaken will be decided by reference to the principles set out in the Mental Capacity Act 2005 and associated guidance. The Official Solicitor will, subject to the usual provision for her costs being met, act as the adult's litigation friend on the issue of whether it is in the adult's best interests for brain stem testing to take place.

iii) If the result of brain stem testing undertaken in accordance with the 2008 Code of Practice is the diagnosis and confirmation of death then, whether or not there was an application to the Court of Protection, the question of best interests is no longer relevant.

iv) In the absence of agreement between treating clinicians and family members with respect to the course of action consequent upon the diagnosis and confirmation of death of the subject adult, a Part 8 application for a declaration of death under the inherent jurisdiction should be made promptly in the Family Division of the High Court, to which application the CPR will apply. The application should be determined as soon as practicable after the diagnosis and confirmation of death.

v) In circumstances where best interests are no longer relevant, the narrow issue for the court to decide on the Part 8 application is whether the patient has died, requiring the court to consider the results of the brain stem testing undertaken and ascertain whether the tests were undertaken in accordance with the 2008 Code of Practice.

vi) Ordinarily, the applicant will be the relevant NHS Trust and the respondent(s) will be the family member(s) seeking to dispute the outcome of the brain stem testing. In circumstances where, following brain stem testing in accordance with the 2008 Code of Practice that diagnoses and confirms death, best interests are no longer engaged and the issue before the court is a narrow one, it will not ordinarily be necessary for the subject adult to be joined as a party to the proceedings. The issue of whether the Official Solicitor agrees to act as litigation friend will therefore not ordinarily arise.

vii) Where the court determines that a declaration of death should be made, the appropriate wording of the declaration of death and ancillary declaration is as follows:

a) [Name of patient] died at XXXX hours on XX [date], irreversible cessation of brain stem function having been conclusively established; he/she having lost the essential characteristics necessary to the existence of a living human person namely (i) the irreversible loss of the capacity for consciousness (i.e. a permanent absence of consciousness), along with (ii) the irreversible loss of the capacity to breathe; thus the inevitable and rapid deterioration of integrated biological function.

b) In the circumstances, it is lawful for a consultant or other medical professional at [the hospital] to (i) cease to mechanically ventilate and/or to support the respiration of [name of patient] and (ii) extubate [name of patient] and (iii) cease the administration of [add medications] to [name of patient] and (iv) not attempt any cardio or pulmonary resuscitation upon [name of patient] when cardiac output ceases or respiratory effort ceases.

DISCUSSION

62. That brain stem testing is the correct legal criteria in this jurisdiction for diagnosing and confirming death was affirmed by the House of Lords in *Airedale NHS v Bland*. That the question of best interests is no longer open to the court following brain stem testing carried out in accordance with the 2008 Code of Practice that has diagnosed and confirmed death was affirmed by the Court of Appeal in *Re M (Declaration of Death of Child)*. For the reasons I have set out above, I am satisfied nothing in the decision in *Barts NHS Trust v Dance* changes this position. In this context, the narrow issue before the court is whether, having regard to the results of the brain stem testing undertaken at 11.51pm on 16 July 2023 and 12.17am on 17 July 2023 in accordance with the 2008 Code of Practice, Mr Casey has died. With deep regret, I must conclude that he has. My reasons for so deciding are as follows.

63. At no point was it submitted in terms on behalf of the Third and Fourth Respondents that the tests undertaken at 11.51pm on 16 July 2023 and 12.17am on 17 July 2023 were not completed in accordance with the 2008 Code of Practice or were otherwise incomplete or incompetent. The purpose of the expert sought by the Third and Fourth Respondent was not, it was apparent, to review the manner in which the brain stem testing had been undertaken, but rather to repeat that testing. In the circumstances, the application for a further expert was not predicated on the original tests not having been carried out properly and in accordance with the terms of the 2008 Code of Practice. Whilst it is apparent that the Third and Fourth Respondents contend that death by reference to neurological criteria is not the same as death in the ordinary sense of the word, and that the validity of brain stem tests is to be doubted, those points were definitively dealt with by the House of Lords in *Airedale NHS v Bland*, by which decision this court is bound.

64. In the circumstances, the height of the Third and Fourth Respondents case must be that the tests undertaken at 11.51pm on 16 July 2023 and 12.17am on 17 July 2023 have returned a false positive in circumstances where the movements demonstrated by Mr Casey and the spontaneous breaths the family say they have witnessed indicate that he is not, in fact, brain stem dead. I regret that I cannot accept that submission.

65. The evidential foundation of that submission is the evidence of the family that they have seen Mr Casey move in ways that convince them he is not brain stem dead. Those movements are described in the statements of Christine Casey, Joe Casey and Macy Jo Phelan to which I have referred above. They are also depicted in a number of the videos that the family invited me to view and which I have viewed. Those videos depict small but perceptible movements by Mr Casey, in particular the slight turning of his head, movement in his hands and arms and the appearance of 'goose bumps' on his skin. They depict also relatives encountering stiffness when pressing against Mr Casey's arm, described in evidence as "like arm wrestling". Whilst the family contend that many of these movements are in response to being touched or spoken to, there is an inevitable difficulty in assessing the validity of such observations given the clear possibility of a movement born simply of a residual reflex coinciding with a request that the move be made or with a tender touch.

66. Having viewed the videos I have no difficulty at all in seeing why Mr Casey's family and friends have taken his movements as being indicative that his brain stem is not dead. Very sadly, however, having regard to the totality of the evidence before the

court, I am satisfied that they do not demonstrate that the results of the brain stem testing undertaken on 16 July 2023 and 17 July 2023 are wrong.

67. Dr S gave clear and empathetic evidence with respect to Mr Casey's condition. Whilst Mr Bogle sought to suggest that Dr S's use of certain medical terminology more apt for a living patient indicated the Trust also doubted the results of the brain stem testing, I am satisfied that he used such language out of a desire to maintain Mr Casey's dignity and to reduce the family's distress.

68. In broad terms, neither Dr S nor the other clinicians treating Mr Casey dispute the descriptions provided by the family of the manner in which Mr Casey is moving. Dr S and Mr Casey's other treating clinicians do, however, dispute the origin of those movements. In his statement, Dr S made clear as follows:

> "I recognise the descriptions of the movements relayed by the family as broadly consistent with what I and others in the clinical team have observed. I disagree with the family, however, on the matter of what stimulates these movements, and their interpretation. This is the universal opinion of the NICU team. On my assessments (see, for example, Exhibit AH2 and Exhibit AH12), the most prominent movements involve the hands (particularly a weak 'thumbs-up' movement) and arms, which can be triggered by light stimulation (for example, stroking the palm or rotating the wrist), or occur spontaneously or on repositioning. I am aware that other movements, including of the neck and trunk, have been observed during physiotherapy (Exhibit AH13: 'spinal reflexes noted on examination - with chest physio expiratory vibs - head moving to left'). I have not observed or been able to elicit any movements in response to verbal instruction and nor have other members of the clinical team. On 5 September 2023, in a discussion with several members of AC's family at the bedside (including his sister, brother, and mother), I asked if they could demonstrate the movements they have observed, but they declined to do this (Exhibit AH12).
>
> [21] Passive flexion and extension of the upper limbs, particularly at the elbows and shoulders, does elicit an impression of active resistance, but this is not what it is. It is a form of involuntary muscle tension termed hypertonia (spasticity or rigidity), which is an increase in tone (the level of residual tension in 'relaxed' muscles) due to the loss of descending signals from the brain. Hypertonia is a very characteristic finding of central ('upper motor neurone') neurological lesions, which includes lesions to the brain stem. It occurs due to the loss of inhibitory impulses from higher centres."

69. Dr S made clear in his evidence that spinal reflexes are a well recognised phenomena after irreversible loss of function of the brain stem, caused by intact reflex arcs between the body's periphery and the spinal cord, and which do not involve the brain. Dr S further made clear that such intact reflex arcs are revealed after death due to the loss of voluntary or automatic inhibitory signals from the brain. He stated that they can take many forms, including a grasp reflex that is, cruelly in light of its emotive significance, reminiscent of a hand squeeze. Dr S stated that such movement can be complex, with perhaps most complex and dramatic of the spinal reflexes being the 'Lazarus sign' which, although uncommon, involves flexion of both arms to the chest, adduction movement towards the midline of the arms at the shoulders, and crossing of the hands.

70. In these circumstances, Dr S evidence was that the movements observed in Mr Casey are entirely in keeping with brain death-associated reflexes and automatisms or 'brain-death associated movements'. Dr S exhibited to his statement research papers that make clear that each of the movements seen in Mr Casey has been recognised as a brain death associated movement. I accept the evidence of Dr S, particularly in circumstances where I am satisfied that it is strongly corroborated by other evidence.

71. First, in addition to being clearly described in the medical research referred to in Dr S evidence, the phenomena described by Dr S and which he states are being exhibited by Mr Casey, are expressly referred to in the 2008 Code of Practice. At paragraph 2.1 the Code of Practice notes as follows:

> "First, the irreversible loss of the capacity for consciousness does not by itself entail individual death. Patients in the vegetative state (VS) have also lost this capacity (see section 6.9). The difference between them and patients who are declared dead by virtue of irreversible cessation of brain stem function is that the latter 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.
>
> Second, the diagnosis of death because of cessation of brain stem function does not entail the cessation of all neurological activity in the brain. What does follow from such a diagnosis is that none of these potential activities indicates any form of consciousness associated with human life, particularly the ability to feel, to be aware of, or to do, anything. Where such residual activity exists, it will not do so for long due to the rapid breakdown of other bodily functions.
>
> Third, there may also be some residual reflex movement of the limbs after such a diagnosis. However, as this movement is independent of the brain and is controlled through the spinal cord, it is neither indicative of the ability to feel, be aware of, or to respond to, any stimulus, nor to sustain respiration or allow other bodily functions to continue."

72. Further, at paragraph 6.6 the 2008 Code of Practice goes on to make the following further reference to brain death associated movements:

> "Reflex movements of the limbs and torso may still occur in the presence of irreversible cessation of brain function, even after this has been diagnosed. The doctor must explain clearly the significance of these movements to relatives, partners, carers and other staff, who should be given sufficient information and explanation to enable them to understand that they are of spinal-reflex origin and do not represent the higher functioning of the brain."

73. Second, and most importantly, I am satisfied that the level of additional testing and observation that has been carried out, exceptionally, on Mr Casey demonstrates that it is not physiologically possible for the movements seen in Mr Casey to be generated in his brain.

74. As I have set out above, Dr S made clear in his statement, and in his oral evidence that the MRI scan and the CTA scan show that Mr Casey's brain has no blood supply and that the damage it has sustained has destroyed the structures necessary for autonomous response and movement. In these circumstances, Dr S made clear that for Mr Casey to have demonstrated movement in response to a request from a family member would require the neural pathways that transmit sound from the ear to the brain to be intact, and for the area of the brain that processes language and the structures that transmit the instruction to move the limb in response from the brain to the periphery to be likewise intact. The additional testing by way of scans shows that those structures do not now exist in Mr Casey. In short, Dr S stated that the MRI and CTA reveal that Mr Casey has "no circuitry" with which to respond in the manner asserted by the family. In this context, over the course of some eight weeks of observation after brain stem testing confirmed brain stem death (as distinct from the usual 24 to 48 hours) no medical professional has witnessed movements in Mr Casey suggestive of activity in his brain.

75. I reach a similar conclusion with respect to the assertion that Mr Casey has taken spontaneous breaths. I accept the evidence of Dr S that what Mr Casey's family and friends have observed is the detection by the ventilator of a perturbation of bias flow in the ventilator circuit which, depending on ventilator settings, could trigger a ventilator-driven breath. Dr S evidence was that when the ventilator is set to detect minimal changes in this regard, it is common for there to be 'artefactual' triggered breaths and that this is very common in ICU, where it is usually desirable to minimise the effort required by spontaneously-breathing patients, knowing that this will be at a cost of some artefactually-triggered breaths. Dr S further made clear that artefactual breaths can be caused by a number of things and are features of treatment on a NICU, including the slightest movement of the patient's body, leaks in the breathing circuit or internally by the heart beating. It is for this reason that the apnoea tests that form part of the 2008 Code of Practice are performed off the ventilator.

76. Once again, I am reinforced in accepting the evidence of Dr S by the additional testing that has been undertaken on Mr Casey. In light of the view expressed by the family that Mr Casey was taking breaths, clinicians disconnected him from his ventilator on several occassions and attached him to a low-resistance breathing circuit. That circuit would have revealed spontaneous breathing if it were to be present. It did not. Again, the additional testing undertaken by way of scanning further supports the conclusion that, by reason of the catastrophic damage to his brain, Mr Casey does not have the "circuitry" to breathe on his own. Again, over the course of the exceptional period of eight weeks of observation, no spontaneous respiratory effort has been observed, either during formal brain stem testing or subsequent informal tests at the request of the family.

77. The 2008 Code of Practice provides as follows with respect to the significance of continued of biological activity following a diagnosis and confirmation of death reached as the result of brain stem testing undertaken in accordance with that Code of Practice:

> "In short, while there are some ways in which parts of the body may continue to show signs of biological activity after a diagnosis of irreversible cessation of brain stem function, these have no moral relevance to the declaration of death for the purpose of the immediate withdrawal of all forms of supportive therapy. It is for this reason that patients with such activity can no longer

benefit from supportive treatment and legal certification of their death is appropriate."

78. Whilst I understand fully the conclusions that the family and friends of Mr Casey have, in their sorrow, drawn from his movements and apparent responses to the ventilator, having regard to the totality of evidence before the court, I am also satisfied that what the family are seeing are in fact well recognised base reflexes that can survive brain stem death. Cruelly, the flattering voice of hope convinces those that love Mr Casey that these are signs that Mr Casey is not dead. With regret, I am satisfied that the brain stem testing undertaken, in accordance with the 2008 Code of Practice, on 16 July 2023 at 11.51pm and repeated on 17 July 2023 at 12.17am demonstrate that he is.

CONCLUSION

79. It is with very great sadness that I must accordingly conclude that Mr Casey died on 16 July 2023 at 11.51pm. I understand that this will come as a bitter disappointment to Mr Casey's family and friends.

80. The now blurred boundary between life and death can be delineated by reference to philosophy, to ethics or to the cardinal tenets of the world's great religions. But the task of this court is to consider whether Mr Casey has crossed over that boundary for the purposes of the law. For the reasons I have given, I am satisfied having regard to the brain stem testing undertaken in accordance with the 2008 Code of Practice that he has. I recognise that this is a tragedy for his family and friends and, whilst I am certain that it will offer little comfort, they have my profound sympathy.

81. In the sad circumstances of this case, I make the following declarations on the application of the Trust which, for the avoidance of doubt, I order pursuant to CPR r. 21.3(4) shall take effect notwithstanding that Mr Casey does not have a litigation friend in the circumstances I have set out above:

    i) Andrew Casey died at 23.51 hours on 16 July 2023 when irreversible cessation of brain stem function had been conclusively established, he having lost the essential characteristics necessary to the existence of a living human person namely (a) the irreversible loss of the capacity for consciousness (i.e. a permanent absence of consciousness), along with (b) the irreversible loss of capacity to breathe, thus the inevitable and rapid deterioration of integrated biological function.

    ii) In the circumstances, it is lawful for a consultant or other medical professional at the hospital part of the St George's University Hospitals NHS Foundation Trust to (a) cease to mechanically ventilate and/or to support the respiration of Andrew Casey, (b) to extubate Andrew Casey, (c) cease the administration of medication to Andrew Casey and (d) not attempt any cardio or pulmonary resuscitation upon Andrew Casey when respiration and cardiac output ceases.