Neutral Citation Number: [2020] EWHC 5 (Fam)

Case No: FD19P00674

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 28/01/2020

Before :

MRS JUSTICE LIEVEN

- -

Between:

MANCHESTER UNIVERSITY NHS FOUNDATION TRUST

Applicant

and

(1) MIDRAR NAMIQ

First Respondent

and

(2) MR KARWAN MOHAMMED ALI

Second Respondent

and

(3) MS SHOKHAN NAMIQ

Third Respondent

- -
- -

Mr Neil Davy (instructed by **Hill Dickinson LLP**) for the **Applicant**
Ms Maria Stanley (instructed by **CAFCASS**) for the **First Respondent**
Mr Bruno Quintavalle (instructed by **Barlow Robbins**) for the **Second and Third Respondents**

Hearing dates: **20, 21 and 22 January 2020**

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Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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The Honourable Mrs Justice Lieven DBE :

1. This is an application by Manchester University NHS Foundation Trust (the Trust) for declarations as follows;

> *Midrar Namiq has no capacity to consent to, to refuse, or to make decisions about the medical treatment he should receive, namely the administration of mechanical ventilation.*
>
> *It is lawful for Manchester University Hospital NHS Foundation Trust to make arrangements for his mechanical ventilation treatment to be withdrawn to allow him a kind and dignified death.*

2. The Trust was represented before me by Neil Davy, the First Respondent, Midrar, through his Guardian (John Power) by Maria Stanley of CAFCASS, and the Second Respondent (the Father) and the Third Respondent (the Mother) by Bruno Quintavalle. The Third Respondent had the assistance of a translator. There was some lack of clarity after the hearing as to whether Mr Quintavalle had been representing the Mother. However, as there was no difference in position before the court between the Mother and the Father, and Mr Quintavalle assured me by email after the hearing that he had been representing the Mother at the substantive hearing, I will record him as having done so. I am very grateful to counsel and Ms Stanley for the sensitive way they presented a very difficult case.

3. The facts of the case are tragic and one can only have the greatest sympathy for what the parents are going through. Midrar was born at full term, but his Mother's membranes had ruptured on the way to hospital and there was a cord prolapse, which meant that oxygen was cut off to his brain. He had an undetectable heart rate and no respiratory output when born, his heart was restarted but he has been on a ventilator at the Neonatal Intensive Care Unit (NICU) since his birth. Three brain stem death tests dealing with death by neurological criteria (DNC) have been carried out, the first on 1 October 2019 and each has concluded that Midrar is brain stem dead. The Trust wishes to take him off the ventilator and allow his life to come to an end, whereas the parents wish him to remain on the ventilator.

4. The issue I have to decide is whether Midrar is dead, according to DNC as set out in the relevant clinical guidance, and therefore the ventilator can be removed. The Trust argues this is not a best interests analysis under the inherent jurisdiction, because if Midrar is dead then best interests do not arise. Both Mr Davy and Ms Stanley agreed that if I concluded that Midrar did not meet the DNC then it would not be appropriate or fair on the family for me to go on to consider best interests, as a separate legal test. But, Mr Power in his report to the court had analysed Midrar's best interests and

concluded that it was in Midrar's best interests that the ventilator should be removed and his life come to an end. Mr Quintavalle argues that best interests are relevant to whether I make the declarations sought.

The factual position

5. Immediately after Midrar was born he was successfully intubated and a slow heart beat was heard. He was transferred to the Neonatal Intensive Care Unit (NICU) and has remained there since. I would like at this stage to pay tribute to the care he has received and the commitment of the staff in the Unit who do what must be an enormously difficult and emotionally draining job. From the evidence that I have heard it appears that Midrar's heart and organs have continued to function in large part because of the expert care he has received from staff in the most difficult of conditions.

6. Midrar was diagnosed with severe hypoxic ischaemic encephalopathy caused by the loss of oxygen to the brain during his birth. An EEG was carried out on 19 September and that found *"CFM [continuous electronic fetal monitoring] severely abnormal … no regular breathing".*

7. Discussions commenced with the parents from 21 September about stopping the intensive care support. The parents at that stage, and subsequently, did not agree, referring to their religious beliefs as Muslims.

8. An EEG was carried out on 23 September, which reports that: *"This resting EEG shows unreactive very low amplitude diffuse poorly formed much attenuated tracing which contains mainly ECG artefact and movement artefact. No clearly appreciated cerebral activity is noted. No sub-clinical or clinical seizure activity is seen… the findings give strong support to severe diffuse hypoxic encephalopathy".*

9. On 24 September an MRI scan was carried out which found "*global brain injury affecting entire cortex and deep grey nuclei which would be supportive for prolonged insult…".* At the end of September further discussions were held with the parents, and they are recorded as saying that their Imam had advised them not to take Midrar off the ventilator, and that as long as his heart continues to beat they are hopeful of him getting better.

10. The first and second DNC tests were carried out on 1 and 2 October by Dr E (consultant neonatologist) and Dr B (consultant paediatrician at the PICU). I will describe the DNC criteria and test below. The testing indicated that Midrar was brain stem dead. A second DNC test was carried out by the same doctors the following day and the results confirmed the findings.

11. The parents instructed solicitors on or about 6 October. They both remained strongly opposed to turning off the ventilator and said they wanted to take Midrar home so that he could be ventilated at home. The Trust suggested getting an independent consultant from another Trust to review the position, and Dr Y (consultant neonatologist) at

Liverpool Women's Hospital was instructed. He examined Midrar and reviewed the clinical notes on 29 October and his opinion states;

> *"Midrar has no prospect of recovery from his injury. He will not regain consciousness. He will not regain the ability to breathe independently or survive without mechanical ventilation. He has no perception of the world around him and this will not return.*
>
> *His heart and circulation continues to function only because of the mechanical ventilation he is receiving and the excellent clinical care that he continues to receive. This circulation is sustaining the function of his other organ systems, but his brain is not functioning and will not recover.*
>
> *Eventually, Midrar's other organ systems and his heart will also die as a consequence of this injury, even if mechanical ventilation is continued. He will eventually develop ventilator associated pneumonia. He will start to develop muscle wasting and joint contractures. It is likely that internal homeostasis will be disturbed as he no longer has central control of endocrine or autonomic functions. It may be possible to manage some of these complications by medical intervention. This is likely to require repeated reintubation of the trachea, chest physiotherapy and airway suction, repositioning and nursing care to maintain skin integrity, multiple blood tests, repeated venous cannulation and antibiotic administration, escalation of ventilator settings and oxygen administration and an increasing number of drugs to be administered.*
>
> *Midrar is unconscious and has no appreciation or perception of the world around him. I do not believe that he has the capacity to feel pain or distress, so this deterioration will not be distressing for him. It will however, be an undignified and unkind way to allow his death to take place. It will also place a significant burden of distress onto his family and onto those who are caring for him given the futility of these interventions and the associated unkindness."*

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12. Dr Y gave evidence before me. He explained that he had not undertaken a further DNC test but he had conducted a review of the relevant notes as well as examining Midrar. I set out his conclusions below.

13. On 4 November Dr B and Dr M (consultant neonatal intensivist) carried out the third DNC test in the presence of the parents and with Dr G also in attendance. The results confirmed the findings of the two earlier tests, namely that Midrar was brain stem dead. A further MRI scan was carried out on 5 November and that concluded;

> *"catastrophic appearances with interval brain liquefaction including brainstem supportive for brainstem death".*

14. The Trust made its application to the Court on 29 November and the matter came before MacDonald J on 17 December. He ordered that there be a two day final hearing starting on 20 January, and a directions hearing on 13 January, both before me.

15. The parents' first solicitors had withdrawn at the end of November because they did not have a legal aid contract. The parents briefly instructed Irwin Mitchell and then moved to their current solicitors on or about 18 December.

16. The matter came before me on 13 January 2020. I adjourned that hearing because there was no interpreter for the Mother and the matter was relisted on the afternoon of 14 January. At that hearing Mr Quintavalle applied for an adjournment, in summary on the grounds that the Father wanted to instruct an independent expert, the legal aid application had not been determined and there was insufficient time to prepare for the hearing. I refused that application in a reasoned judgment and there was no appeal. I did email the LAA the following day and asked them to expedite the determination of the Father's application for legal aid, which they did. Legal aid was granted on 15 January.

17. On the morning of 20 January Mr Quintavalle made a further application for an adjournment which again I refused in a reasoned judgment. An application for permission to appeal was made, but refused by Moylan LJ on 21 January.

The relevant guidance

18. There are two Codes of Practice which are relevant to Midrar's situation. Firstly, "A Code of Practice for the Diagnosis and Confirmation of Death", dated 2008 and produced by the Academy of Medical Royal Colleges AoMRC). This Code of Practice is referred to extensively by Hayden J in *Re A (a child)*. The 2008 Code expressly says that it does not apply to babies under 2 months of age. It is therefore supplemented by guidance called "The diagnosis of death by neurological criteria in infants less than two months old" dated April 2015 and produced by the Royal College of Paediatrics and Child Health (RCPCH).

19. The 2015 Guidance builds upon the 2008 Code so it is appropriate to start with the 2008 Code.

> *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 such as, for example, cardiac arrest.*
>
> ***2.1 Death following the irreversible cessation of brain-stem function***
>
> *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.*

Three things should be noted in this regard:

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.

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.

The current position in law is that there is no statutory definition of death in the United Kingdom. Subsequent to the proposal of the 'brain death criteria' by the Conference of Medical Royal Colleges in 1976,3,4 the courts in England and Northern Ireland have adopted these criteria as part of the law for the diagnosis of death.5,6 There is no reason to believe that courts in other parts of the United Kingdom would not follow this approach.

Chapter 6: The Diagnosis of Death Following Irreversible Cessation of Brain-Stem Function

…Concern is sometimes expressed over continuing function within the brain-stem, occurring beneath the level at which any motor, somatosensory or breathing reflexes can be elicited and also over

> *continuing function in other parts of the brain. However, as has already been indicated, both are irrelevant when evaluating function against these clinical criteria of death resulting from irreversible cessation of brain-stem function, which demonstrate the permanent absence of consciousness and thus the ability to feel or do anything, along with the inevitable and rapid deterioration of integrated biological function.*

20. The 2008 Code states that the criteria should not be applied to babies under the age of 2 months because of the difficulty of diagnosing DNC in babies at this very young age. The Code also says that the test must be performed on two occasions by the same two nominated doctors.

21. In 2015 the 2008 Code was supplemented by the 2015 Guidance from the RCPCH which applied the 2008 criteria to infants under the age of 2 months but with one additional criterion. The 2015 Guidance requires an adjustment to the apnoea test in order to establish respiratory unresponsiveness. The Guidance makes clear that no ancillary tests are required to make a diagnosis of DNC in infants under two months.

The law

22. In *Re A (a child)* Hayden J addressed a very similar position to that before me, whether a child had met the DNC criteria set out in the 2008 Code. He applied the tests in the Code in order to determine whether the child was dead. Having recited the relevant parts of the Code, and then having determined that the question of whether the child was dead was ultimately one for the High Court and not the Coroner, the Judge said;

> *For the avoidance of doubt all the advocates here have agreed that the High Court Family Division has the relevant jurisdiction. This clearly exists both under the parens patriae (which has its very origins in the responsibility, for 'a ward of court' and the body of the ward) and pursuant to an application for declaratory relief made under the inherent jurisdictional power. The interrelationship between the two is sometimes subtle but, either separately or together, they authorise this court to make declarations in respect of what I must now regard as Child A's body.*
>
> *Whilst expressing profound respect for the father's views, the time has now come to permit the ventilator to be turned off and to allow Child A, who died on 10th February, dignity in death. For those reasons, I propose to make the declarations sought by the Trust, with the indicated amendments, confident that this hospital will do everything they can to make this inevitably painful process as dignified as possible for all concerned. I would only add my profound condolences to Mr and Mrs A and to Child B and Child C.*
>
> *I am very clear that should a difference of view arise between treating clinicians and family members in circumstances where assisted ventilation is continuing, any dispute, if it cannot be resolved*

> *otherwise, should be determined in the High Court, not under coronial powers.*

23. In *Oxford University NHS Trust v AB* [2019] EWHC 3516 Francis J was again addressing whether the 2008 Code was met. He said at [21];

> *Secondly, the fact is, as I have already identified, tragically Dr AB is already effectively dead according to the definition from the Code of Practice which I have just read out.*
>
> *Thirdly, (and I use the word "futile" only in the correct medical and legal sense), treatment would be futile. Continuing respiration would be futile because it will be pointless; it is impossible that anything will happen to bring AB back.*
>
> *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.*

24. Mr Quintavalle argues that *AB* is inconsistent with *Re A* because Francis J did address best interests at [2]. I note that Francis J did not make any reference to a best interest analysis, or that he thought he was differing from Hayden J. The reference at [2] is only the declaration which had been sought, but there is no further reference to best interests. Plainly in both cases the matter came before the Court as one of great urgency, and certainly *AB* is an extempore judgement. In my view there is no difference in the analysis of the two cases and in both the issue was whether the DNC criteria were met and best interests is not the relevant test.

The Parties' positions

25. The Trust's position is straightforward. Midrar has been found to be brain stem dead following tests in accordance with the appropriate clinical guidance. Those tests were carried out by appropriate professionals and they were undertaken in accordance with the relevant clinical guidance, as set out above. The Trust argues that there are no other indicators which give any reason to believe that the output of the tests was unreliable. In those circumstances the court should make the declarations sought, and set out at para 1 above. I will explain the Trust's responses to the various points made by Mr Quintavalle when I come to my conclusions.

26. Ms Stanley supported the Trust's position.

27. Mr Quintavalle argues that there is no statutory definition of death and when the Court's inherent jurisdiction is invoked to declare a person dead then the court must apply a best interests test. He says *Re A* was wrongly decided. He then breaks deaths down into three categories; those where the medical practitioner simply signs a death certificate under the Births and Deaths Registration Act 1953; those that fall within the DNC

criteria in the 2008 Code; and a situation such as Midrar's where there is no rapid deterioration of the body, which was not anticipated by the 2008 Code. He refers, and relies heavily on para 6.4 of the Code and the fact that Midrar's heart has continued to beat for four months without any aggressive support. The code says;

> *Even if ventilation and cardiovascular support are continued, both adults and children will ultimately suffer cessation of heart beat. Often this occurs within a few days but may take weeks or even months, if aggressive support is maintained…*

28. He then argues that in these medically complex cases it would be inappropriate for the Court to deal with the case on a factfinding basis, rather than applying a best interests analysis. This is because the Court is being invited to determine complex science; it involves the Court being asked to look at the matters where Parliament has given no statutory basis for determining death; and it fails to provide the patient with article 2 (ECHR) protection. Therefore, he says that the Court should apply a best interests test.

29. If he is wrong on the above submission he argues that when the Court is determining whether death has occurred the court should consider the matter with "anxious scrutiny" rather than simply applying a balance of probabilities approach.

30. He then raises a number of points on the evidence to show that the DNC criteria cannot be found to be met. I will deal with these below when I consider the evidence.

Conclusions on the legal approach

31. I do not accept Mr Quintavalle's argument that I should undertake a best interests analysis. There is no statutory definition of death, presumably at least in part because it is often hard for law to keep up with developments in medical science. The test for whether a patient is dead is in the first instance one for medical professionals. When the patient is in the tragic situation of someone like Midrar the relevant clinical tests are those set out in the 2008 Code, in particular section 6. This was the approach of Hayden J in *Re A (a child)* and followed by Francis J in *Re AB*. I do not think that Francis J was differing from Hayden J, and he plainly did not think so.

32. That the legal question is one of the application of the DNC criteria follows from previous authority and the terms of the Code. It also makes complete sense. If a patient is brain stem dead then there are no best interests to consider. Once those criteria are met the patient has irreversibly lost whatever one might define as life; and any other functions (such as the heart continuing to beat) have "no moral relevance", as the Code says at para 2.1.

33. I accept Mr Quintavalle's argument that in theory that could put the Court in the difficult position of having to determine purely medical issues, and potentially very complex ones. However, I also accept his argument, with which the Trust agreed, that the question of whether the criteria are met should be approached with "anxious scrutiny". I adopt that terminology from other areas of human rights law, but when deciding whether or not a patient is dead and their ventilator can be removed it must be

the case that the Court applies a very careful approach. The burden of proof is on the Trust, and in reality if a Court had a doubt as to whether the DNC criteria were met, then it would be most unlikely to grant the declaration sought.

34. In my view article 2 adds nothing to this analysis. To put the matter at its most stark, if the patient is clinically dead then there is no life to protect. Plainly the Court would have to be satisfied that the Code itself protected life to meet the State's duties under article 2, but it is apparent that the Code (and the 2015 Guidance) were drawn up after a thorough and careful process by a body of highly competent experts.

35. For these reasons the approach I will apply below is that (1) the burden of proof is on the Trust; (2) the standard of proof is the balance of probabilities but the Court should apply anxious scrutiny to the evidence; (3) no best interests analysis is appropriate.

Analysis of the evidence

36. I heard medical evidence from four clinicians. Dr G (consultant neonatologist in the NICU) who has been Midrar's lead consultant on the NICU and first attended him about 3 minutes after he was born. She has been a consultant neonatologist since 2003. Dr M (a consultant neonatologist at NICU) who carried out the third DNC test. Dr B (a consultant intensivist at PICU) who carried out all three DNC tests. Dr Y (a consultant neonatologist at Liverpool Women's Hospital) who was asked to give an independent opinion in the hope of reaching an agreement with the parents and therefore was not a treating clinician, but equally was not appointed as an independent expert in the litigation. I did not hear evidence from Dr E because he was abroad throughout the period of the hearing.

37. I will set out the detail of some of the clinical evidence below when I deal with the various points raised. However, I make clear here that all four of the medical witnesses were in my view eminently well qualified to give the evidence they did. Their evidence was entirely clear and consistent, and none of them had any doubt that Midrar was brain stem dead and that he was not capable of breathing. Dr G, who has been Midrar's lead consultant since very shortly after birth was plainly doing her utmost to maintain as good a relationship as possible with the parents, even in these very difficult circumstances.

38. I heard evidence from Mr Ali. He plainly cared passionately for his son, and was driven by a very human desire to maintain hope in all circumstances and not to give up on him. Mr Ali has a degree in biomedical science and had examined the medical records and watched the monitors in detail. He and the Mother's love and commitment to Midrar cannot be in any doubt. However, his desire to cling on to any hope does appear to have led him to interpret material in the way he wanted rather than at times listening to the evidence. An example was that he was convinced that Midrar had been sedated for long periods of his time in NICU, including during the tests. There was simply no evidence to support this suggestion, which was a highly damaging one to the Trust. The drug charts have been disclosed and save for the first two days of life no sedatives had been administered, as Mr Quintavalle accepted. Mr Ali also had alleged that various clinicians had a conflict of interest because they had some involvement in organ donation. Again this is a highly damaging (and hurtful) allegation for which there was

no evidence. Again this was not pursued by Mr Quintavalle. I refer to these points because although the greatest sympathy must be extended to parents, that does not mean that they can have a free rein to make allegations against the doctors who are treating their child, where there is no basis for such allegations.

39. It is the Father's case that Midrar is not brain stem dead and therefore the declarations should not be made. A number of points are raised in support of this case and I will set out each one, then the evidence on behalf of the Trust and my conclusions on the points raised. I will then set out my overall conclusions.

40. Mr Quintavalle's arguments fall under two heads. Firstly, he argues that the DNC tests are not reliable because Dr E was not suitably qualified; it is not clear that the apnoea test was carried out in the right circumstances; and parental consent was not obtained for the tests. Secondly, Mr Quintavalle argues that there is evidence that shows that Midrar is not brain stem dead.

41. Mr Quintavalle argues that Dr E was not suitably qualified to carry out the first and second DNC tests and refers to a recording the Father made of a conversation with Dr E before the first test was carried out. It is correct that Dr E had not carried out a DNC test previously, and had not been on any training course but had watched a video of the tests. He was undoubtedly appropriately qualified as a consultant neonatologist of the sufficient number of years qualification in accordance with the Code. There is no requirement for any specific training to be undertaken and for each individual there will necessarily be a first time they undertake the test. It is worth noting that the tests are not in themselves complicated, but involve close observation of the patient. Dr B, who has carried out DNC tests on a number of occasions, said that in her view Dr E was appropriately qualified and carried out the tests appropriately. She also made clear that it is good practice for one of the treating clinicians to undertake the tests, so that one of them knows the child.

42. It is important to note in this respect that children in Midrar's situation, and the conducting of these tests on very young babies, is very rare. Until the 2015 Guidance was produced DNC tests were not carried out on babies under 2 months old. Dr B said that so far as she was aware, in the year 2018/19 only one child of that age was DNC tested. It is therefore inevitable that very few doctors will have much experience of conducting the tests on very young babies, and happily not even that much experience on the slightly older children.

43. In terms of meeting the precise requirements of the 2008 and 2015 guidance I can see no basis for finding that Dr E was not qualified. As far as his competence is concerned, Dr B, who is herself very experienced in carrying out DNC tests on children said that she had no concerns about Dr E's competence to carry out the tests. I therefore reject the argument that the tests were invalid because Dr E was not appropriate to carry them out.

44. The second issue raised concerns whether Midrar was in the appropriately oxygenated condition when the apnoea test was carried out. Mr Quintavalle pointed to the fact that the PaO2 for the apnoea test needs to be above 10kPA, but when the DNC was started the capillary blood test showed only 8.1kPA. However, this point goes nowhere because, as Dr B pointed out, the key issue is that Midrar was 100% oxygenated before

the apnoea test element was commenced. Therefore, Dr B could be entirely confident that his Pa02 levels were above 10 by the time that stage of the overall test was reached.

45. The third issue is that Mr Quintavalle argues that the DNC tests could only be carried out if the parents had given fully informed consent. He relies on *Glass v UK* to argue that the tests would be invalid without such consent. In my view this argument is wrong for a number of reasons. Firstly, the parents were aware that the tests were going to be carried out probably that day, as is shown by the transcript of the conversation with Dr E, and the Father did ultimately accept this. The transcript does not suggest that the Father or Mother said the tests should not go ahead. Further, the parents were fully informed as to the purpose of the tests, so in my view the issue about "informed" consent goes nowhere on the facts of the case. Secondly, I do not think there is any requirement for written consent from the parents, or for the information to be written down. There is no such requirement in the Code. *Glass* is dealing with a very different situation, where the issue was the withdrawal of certain treatment. It is not clear to me that consent would necessarily have to be given for a test at all. But, I do not have to decide that issue because the parents undoubtedly knew that the test was to be carried out, and knew what the test was about. Therefore they were given the appropriate information, and on the facts of the case their consent can be inferred from their conduct. Thirdly, and in any event, even if the tests should not have taken place because of lack of consent that does not mean that the outputs of the test would not be admissible before me. I am being asked to decide a factual question as to whether Midrar is dead, and lack of consent would not vitiate the evidence that goes to that issue.

46. For all these reasons I find that the tests were appropriately carried out, and carry full evidential weight before me.

47. The final issue is that the Father and Mother do not believe that Midrar can be brain stem dead because they have seen him making movements on a number of occasions; he was seen to be sweating during the circumcision that took place last week, and they believe the output screen from the ventilator shows that Midrar has been attempting to breathe. They also argue that the fact that his organs (including his heart) have continued to function for such a long period after the first DNC test indicates either that the outcome of the test should not be followed or that the test was wrong. For these reasons Mr Quintavalle asserts that Midrar cannot be brain stem dead.

48. There is no dispute that Midrar does exhibit some movements of his limbs and eyes on occasion. Dr G and Dr B both explained that the movements that the parents and the clinicians have seen are not movements emanating from brain activity, but rather are reflexes from the spinal cord. Dr G explained that in patients who are brain stem dead their spinal cord nervous system (the peripheral nervous system) can continue to give rise to reflexes, which is what have been observed. Both Dr G and Dr B said this response was quite normal in such patients.

49. Mr Quintavalle argues that Midrar has attempted to breathe and points to observed movements of his chest and screenshots of the ventilator output which shows some brown areas which could indicate small exhalations. The Trust witnesses say that the chest movements are the same phenomenon as responses by the peripheral nervous system rather than any brain stem activity. There may be some very small movements of the chest but these are not attempts to breathe. Dr G was very clear that when the

apnoea test is being undertaken and the CO2 levels are allowed to increase, the patient, even a small baby, will make a clear and obvious gasp for air and that this is definitely not what was seen with Midrar at the third DNC test, when the apnoea test was being undertaken and Midrar's chest moved. Dr B, who has carried out the DNC tests on a number of occasions and has treated a very large number of very sick young babies, was completely clear in cross examination that what was seen was not an attempt to breathe.

50. It is important to emphasise in this regard, particularly as the parents have no expert of their own, that Midrar has been treated by a large number of highly experienced clinicians, both doctors and nursing staff. The finding that Midrar cannot breathe does not rest on the evidence of one or two clinicians, but on the four consultants who gave evidence before me and the fact that none of the multiple healthcare professionals who have been treating him over the last four months have recorded any suggestion that he is capable of breathing unaided.

51. The Father argues that Midrar cannot be brain stem dead because his heart (and other organs) have continued to function largely unaided some months after he failed the first and second DNC tests and because he continues to grow. Mr Quintavalle points to a 1986 study from Osaka University where it is suggested that once patients are brain stem dead they would only be expected to survive for a short period, and this study is referenced in the 2008 Code.

52. The Trust witnesses make the following points. Firstly, it is extremely rare for an infant to be kept on a ventilator for a prolonged period after they have been found to be brain stem dead. In fact, it appears that Midrar may have spent the longest time in this condition of any recorded case in the UK. This means that it is unsurprising that there is no documentation on how long the heart will continue to beat in that situation, because it virtually never arises. This is not an indicator that Midrar is not brain stem dead, but rather that the unhappy situation that has arisen in this case is exceptionally rare. Dr Y explained that the heart muscle will continue to beat regardless of whether there is neurological integrity.

53. Secondly, both Dr G and Dr B said they were aware of a number of cases in the medical literature where adults have continued to be ventilated for long periods after they have been found to be brain stem dead and there are cases where the heart has continued to beat for up to 180 days. It seems that most, if not all, of these cases are ones of pregnant women where the woman who is brain stem dead, is kept on a ventilator so that the foetus can develop to the point where it can be born at a reasonable gestation period. This does strongly suggest that the fact that Midrar's heart and other organs continue to function without any aggressive form of drug treatment does not indicate that he is not brain stem dead.

54. Thirdly, the Osaka study dates back to 1986 and the care of patients on ventilators has much improved since then.

55. I note generally that Dr Y told me that he had examined Midrar and there had been no tendon or gag reflexes, and, when the ventilator was reduced, no effort to breathe. He said he could detect no evidence of any neurological functions.

56. Midrar's body will continue to grow as long as he remains on the ventilator and is fed. However, Dr G explained that his head is shrinking because his brain is contracting. She was entirely clear that in a baby who had suffered a serious brain injury but was not brain stem dead the brain would continue to grow, albeit potentially more slowly than would normally be the case.

Conclusions

57. Sadly, I have no doubt that Midrar is brain stem dead and meets the DNC criteria. That those criteria should be applied is established in *Re A (a Child)* [2015] EWHC 443 and in my view that is plainly correct. Equally, the 2015 Guidance, which was not before Hayden J, was drawn up by an expert panel after careful consideration and must also set out the relevant tests both in medical practice and now in law.

58. The medical evidence is both clear and consistent. Three DNC tests have been undertaken and they all reach the same conclusion. For the reasons I have outlined I do not find that there is any substance in any of the criticisms advanced by Mr Quintavalle on behalf of the Father of either Dr E's competence to carry out the tests or of whether they were carried out in the correct conditions.

59. To the degree that it is relevant, and under the clinical guidance it is not relevant, the conclusions of the DNC tests are entirely supported by the EEGs that have been carried out and the two MRI scans. These show respectively, no electrical activity in the brain and that the structure of the brain stem is fundamentally undermined and subject to liquification. This is undoubtedly irreversible.

60. It is perfectly understandable that the parents should cling to hope by pointing to Midrar's movements, including chest movements. However, all four consultants who gave evidence said there was an obvious and well-known reason for these movements, namely spinal cord reflexes. Equally, the three clinicians who were present at the third DNC test were entirely clear that Midrar was not at the time showing a respiratory response by trying to breathe. The medical evidence could not have been clearer or more unequivocal on this point. I remind myself again that Dr G, Dr M and Dr E are all highly experienced clinicians who have treated 100s of sick young babies. I have no reason not to accept that they will be well able to tell if a baby is showing a respiratory response.

61. For all these reasons I will make the declarations sought. I will deal with the reporting restriction order in a separate judgment.