Supreme Court of New South Wales

TS & DS v Sydney Children's Hospital Network ("Mohammed's case") [2012] NSWSC 1609 (24 December 2012)

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Case Title:	TS & DS v Sydney Children's Hospital Network ("**Mohammed**'s case")
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Before:	Garling J
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	Uniform Civil Procedure Rules
Cases Cited:	Breen v Williams [1996] HCA 57; (1996) 186 CLR 71 MAW v Western Sydney Area Health Service [2000] NSWSC 358, (1999) 49 NSWLR 231 Northridge v Central Sydney Area Health Service [2000] NSWSC 1241; (2000) 50 NSWLR 549 Re B (A Minor) (Wardship: Sterilization) [1988] 1 AC 199 Re C (a minor) (Wardship: Medical Treatment) [1989] 2 All ER 782 Re F (Mental Patient: Sterilization) [1991] UKHL 1; [1990] 2 AC 1 Re J (a Minor)(Wardship: Medical Treatment) [1990] 3 All ER 930 Rogers v Whittaker [1992] HCA 58; (1992) 175 CLR 479
Category:	Principal judgment
Parties:	TS and DS Sydney Childrens Hospital Network
File Number(s):	2012/00398635
Publication Restriction:	Publication of the names and identities of the applicants and their son is restricted so that they can only be identified by the pseudonyms contained in the judgment.

JUDGMENT

1. At 3.10pm on Friday 21 December 2012, TS made telephone contact with me as the Duty Judge, on behalf of himself and his wife DS, to urgently seek an order of the Court, compelling the medical staff at The Children's Hospital at Westmead ("the Hospital") to treat his seriously ill 9 month old son, **Mohammed**, by means of mechanical ventilation, rather than by treating him only with oxygen delivered through continuous positive airway pressure ("CPAP"). **Mohammed** is and has been since June 2012, an in-patient in the Hunter Baillie Ward at the Hospital.

2. Initially, contact was made by me with the Medical Director of the Intensive Care Unit, Dr Stephen

Jacobe in order to establish the degree of urgency which attended **Mohammed**'s condition and, as a consequence, the hearing of the application. It was clear that there was a high degree of urgency. I then contacted Dr Glen Farrow, the Director of Clinical Governance for the Hospital, whom I was told by Dr Jacobe was the responsible member of staff of the Hospital, to ascertain whether the Hospital was in a position to deal urgently with the application. He agreed that it was.

3. Because **Mohammed**'s parents, TS & DS, were then at the Hospital, as were the treating doctors and all clinical records relating to **Mohammed**, arrangements were made to hold an urgent sitting of the Court in appropriate facilities at the Hospital. The hearing commenced at 6.30pm on 21 December at the Hospital at Westmead, and continued until 9pm that evening at which time I reserved my decision until Monday 24 December 2012. At the suggestion of Dr Farrow, and with the consent of all present, I made an appropriate interlocutory order in the following terms:

"until further order, the Sydney Childrens Hospital Network by its employees, servants and agents are to take all necessary steps including mechanical ventilation when clinically required for the treatment of the respiratory condition of, and the maintenance of life of, **Mohammed**"

4. At the conclusion of the hearing, with the consent of all parties, I visited **Mohammed** in the Hunter Baillie Ward where I was able to observe for myself his condition, the extent of his treatment which was then being provided and his ability to interact with his mother, DS.

5. It is clear that the necessity to deliver this judgment as quickly as is possible will result in reasons for judgment which are not as extensive as they otherwise might be, and less felicitous of expression than if more time were available.

PROCEDURAL MATTERS

6. The court is entitled make any orders for the conduct of any proceedings which appear convenient for the just, quick and cheap disposal of the proceedings: r 2.1 of the Uniform Civil Procedure Rules.

7. Accordingly, I dispensed with the need for the applicants to file or serve a Summons in written form, and permitted the application to proceed upon the basis of an oral articulation of the relief sought and the submissions made orally by both of the applicants.

8. Having regard to the age of **Mohammed**, the nature of the proceedings and the orders being sought, I made an order under the *Court Suppression and Non-publication Orders Act* 2010, that the applicants be referred to by their initials, and that the full name and identity of their son be suppressed, until any further order of this Court. I determined to make this order, of my own motion, in circumstances where none of the parties were legally represented and I considered that such an order was necessary to prevent any prejudice to the proper administration of justice: s 8(a) of the Act. I also formed the view that it was necessary in the public interest for the order to be made, and that interest " ... *significantly outweighs the public interest in open justice."* s 8(e) of the Act. This approach also accords with the usual procedure of this Court in cases involving the health and welfare of a child.

9. As I have said, the hearing was conducted urgently and in facilities provided to the Court at the Hospital. Neither the applicants, nor the Hospital, were legally represented, although they were entitled to be. Both of the applicants were present throughout the hearing. On behalf of the Hospital, the following were present:

(a) Dr Ken Peacock, a specialist paediatrician who is responsible for the team which treats **Mohammed**. Of all the medical staff, it is he who has had the closest connection with **Mohammed**;

(b) Dr Stephen Jacobe, a specialist paediatric intensivist, who is the Director of the Intensive Care Unit at the Hospital. He has examined **Mohammed**, and become familiar with his case, because it is anticipated that **Mohammed** may need to be admitted to the ICU. It is he who would be responsible for the procedures necessary to place **Mohammed** onto a mechanical ventilator;

(c) Dr Nicholas Pigott, who is also a specialist paediatric intensivist, who would be involved with the mechanical ventilation procedures. He had not examined **Mohammed**, but he had familiarised himself with **Mohammed**'s condition;

(d) Dr Glen Farrow, who is the Director of Clinical Governance for the Hospital. He is neither paediatrician, nor an intensivist; and

(e) Professor David Isaacs, who is a Clinical Professor of Paediatrics and Child Health at the University of Sydney, but based at the Hospital. Other than by being present as an observer, he took no part in the proceedings.

10. A slightly less rigid atmosphere than that which usually exists in a courtroom characterised the hearing. It was certainly less adversarial in style than a typical case. But I am satisfied that both parties had an adequate and sufficient opportunity to place all of the facts about **Mohammed**, and the opinions of the applicants and the doctors about what was in **Mohammed**'s best interests before the Court.

11. In those circumstances, it is unsurprising that there were no submissions addressed to any legal issues which arise in proceedings of this kind. Past cases and precedents were not referred to. This is not in any way a criticism of the parties. Far from it. They addressed those matters which they regarded as central to the disposition of the application. However, it is proper to record this fact, so that it can be understood that these reasons for judgment on matters of law have been prepared without the benefit of legal analysis and any research by, and any submissions of counsel.

ORDERS SOUGHT

12. The applicants outlined orally the relief which they wanted the Court to make. They said that what they wanted was an order that the Hospital mechanically ventilate **Mohammed** and not to leave him breathing either naturally, or else only with oxygen being delivered to him, as at present, by the non-invasive method of CPAP.

13. As they were not legally represented, and as it was clear to the Hospital representatives present what relief the applicants were seeking, for the purposes of this judgment, I have expressed the relief sought in this way:

"An order that the Sydney Childrens Hospital Network, by its employees, servants or agents, are to take all steps necessary to place **Mohammed** on mechanical ventilation, and to maintain him on such mechanical ventilation, until such time as his parents consent to the cessation of mechanical ventilation, or else the Court

otherwise orders."

14. The Sydney Children's Hospital Network is the legal entity responsible for the conduct of The Children's Hospital, Westmead. It is convenient to continue in this judgment to refer to the Hospital, rather than the Network, because it is the active entity responsible for the provision of care to **Mohammed**.

MOHAMMED & HIS FAMILY

15. TS is 36 years old. He is married to DS who is 31 years old. They have a daughter who is 11 years old. After many years of waiting and hoping for another child, their son, **Mohammed**, was born on 29 March 2012.

16. TS and DS are obviously educated. They are a part of TS's extended family in Australia. DS's family are all resident overseas. They are articulate and thoughtful parents. Their love for, and devotion to, **Mohammed** is obvious. Although he is in hospital, they are with him every day and care for him as much as they possibly can. They change his nappies and bathe him, they provide suctioning of his air passages when required. They talk to him, adjust his position and do everything that loving and caring parents could possibly do.

17. Importantly, they interact with the doctors and nurses who provide professional care for **Mohammed**. They are appropriately inquisitive of the doctors and nurses. They ask questions and try to keep fully informed about **Mohammed**'s condition, about his diagnosis and his prognosis. They themselves monitor his condition closely.

18. In addition to doing all of this because they are **Mohammed**'s parents, and because they love him deeply, they regards themselves, so it seems to me, as advocates for him. They do this because they want to ensure that he has every opportunity for a full and long life as is possible.

19. When appearing before me, they fulfilled this role admirably and responsibly. They expressed their views clearly, directly and forcefully. When they thought it appropriate they challenged the views expressed by the doctors, and corrected any errors or omissions which they thought were important. They added facts and descriptions of events which they thought were relevant.

20. Whatever be the outcome of this judgment, it cannot be doubted in the slightest that TS and DS have fought for **Mohammed**, and for their own wishes as hard as they possibly can. They have been in all respects model parents.

21. **Mohammed** is very lucky to have such parents.

MOHAMMED'S CLINICAL HISTORY

22. When he was born at Auburn Hospital, **Mohammed** was diagnosed with the mosaic form of Trisomy 21. This is commonly known as Down Syndrome, or Mosaic Down Syndrome. Because he has Mosaic Down Syndrome, it is likely that **Mohammed** is more mildly affected by the syndrome than others, but it is too early to tell with any certainty.

23. According to readily available and reputable medical dictionaries, Down Syndrome is the most common chromosome abnormality in people. It is usually associated with a delay in cognitive development and a

retardation of physical growth. Depending upon the extent of the condition in any one individual, Down Syndrome is associated with readily identifiable facial characteristics.

24. Shortly after his birth, it was established that **Mohammed** also had a cardiac condition known as *Patent Ductus Arteriosus* ("PDA"). This is a condition where a blood vessel, the *ductus arteriosus* does not close after birth as it generally does, but remains open (*patent)*. PDA leads to abnormal blood flow between the aorta and pulmonary artery, two major blood vessels that carry blood from the heart. **Mohammed** has had surgery at the Hospital to correct this condition. The surgery has been successful and there are no further sequelae resulting from his PDA. It is now only of interest as a historical fact. It has no role to play in any assessment of his current diagnosis, or his prognosis.

25. **Mohammed** presented to, and became an in-patient at the Hospital on 12 June 2012. He was then 21/2 months old. With the exception of two day visits to his home, and one overnight visit, he has not left the Hospital. It is now clear, and beyond dispute, that he will need to, and will remain an in-patient in the Hospital. His clinical condition, and his care needs, are such that he has no prospect of returning home.

26. When he was admitted, he had breathing difficulties which were thought to be related to a virus and his PDA. In conjunction with the cardiac repair surgery, extensive testing was undertaken. This has resulted in an initial diagnosis (which continues to be the working diagnosis) of a very rare metabolic disorder which is thought likely to be a mitochondrial defect. Students of basic biology learn that the mitochondria are located in a cell's cytoplasm, and are responsible for the conversion of energy into a form which is usable by the cell for amongst other things, cell division and growth. It can thus be seen that a mitochondrial defect has the capacity to affect the growth of all parts of the human body.

27. Although there are different names for the condition, the initial diagnosis reached by Dr Ken Peacock, a specialist paediatrician who is in charge of **Mohammed**'s care, was that he suffers from *Pyruvate Dehydrogenase Deficiency* ("PDD").

28. This condition, speaking generally, is characterized by a build up of a chemical called lactic acid in the body and, as well, a variety of neurological problems. The build up of lactic acid is a potentially life threatening feature of PDD which can cause nausea, vomiting, severe breathing problems, and an abnormal heartbeat. The neurological problems which are a feature of PDD include delayed intellectual development and delayed development of motor skills, such as sitting and walking. Other neurological problems can include intellectual disability, seizures, weak muscle tone or hypotonia, poor coordination, and difficulty walking. The occurrence of these features depends upon the extent of the condition in the individual patient and their age.

29. In **Mohammed**'s case, he had, and continues to have, significantly elevated blood lactate levels. He has epileptic seizures which are poorly controlled even though two different types of medication are being administered. Imaging studies of his brain, by a Magnetic Resonance scan ("MRI"), have shown that he has extensive changes of the brain.

30. He has what the doctors referred to as a profound developmental delay. As I understand this term, it means a significant lag in a child's physical, cognitive, behavioural, emotional, or social development, when compared to established norms of development across a population.

31. **Mohammed** is unable to be fed normally. That is because he has severe reflux, with the result

that he does not get the benefit of any food ingested through his mouth and into his stomach. All of his feeding occurs through a tube which has been placed through his nose and ultimately into his small bowel. It thus by-passes his stomach and minimizes any reflux. He has been fed at various times on two different diets. One was a ketogenic diet. He has failed to thrive on either of those diets, and although from time to time there is a weight gain, in an overall sense, he is losing weight. Ordinarily, one would expect babies at 9 months of age to be putting on weight and growing physically.

32. Dr Peacock described **Mohammed** has having very limited visual responses. He has concluded that **Mohammed** is effectively blind. **Mohammed** does not respond to noise stimuli. It seems therefore that he is deaf.

33. According to the doctors, **Mohammed** does not respond to touch, unless the contact is painful for him. So he would feel pain from the insertion of a needle or intra-venous cannula. When I saw his mother, DS, tenderly stroking his tiny hand, he did not display any physical reaction. This was as the doctors described it

34. He is hypotonic. This means that he is unable to control his muscles and make them move. He therefore has very limited physical movements. He can't sit up by himself or hold himself in a sitting position if placed there. He can't roll over and generally is described as "very floppy".

35. His present regime of treatment and medication includes the following:

- Oxygen continuously delivered by CPAP. Recently, the amount of oxygen being delivered has been increased from 8cm of water to 10cm of water. This is a measure of the pressure used to deliver the oxygen. It suggests to me that **Mohammed** now requires a higher pressure of oxygen delivery to maintain a satisfactory level of oxygen in his blood;
- Diuretic medication, consisting or Lasix and Aldactone, which is intended to reduce **Mohammed** 's fluid levels. He presently is suffering from pleural effusion which is indicative of congestive cardiac failure;
- Medication to address his seizures. This presently consists of Phenytoin and Keppra. As well, the Ketogenic diet was prescribed in an attempt to address, and hopefully ameliorate, **Mohammed** 's seizures;
- A road based anti-biotic called Augmentin is presently being given to **Mohammed**; and
- From time to time, as necessary, **Mohammed** has been receiving an anti-acidic drug called Losec, and a sedative, called Midazolam.

THE CORRECT DIAGNOSIS OF MOHAMMED 'S CONDITION

36. As I have earlier said, the initial and working diagnosis adopted by Dr Peacock for **Mohammed** was, and remains PDD.

37. The applicants drew attention to the fact that initial tests which were carried out, and which were expected to confirm the diagnosis, did not do so. Further tests by way of biopsies which can be performed may take some months before results are available. This is because of the nature of the tests. The applicants say, therefore, that the diagnosis cannot be confirmed until the results of these further tests are available. It follows, they say, that in the absence of such a confirmed diagnosis, predictions as to **Mohammed** 's future, and his likely outcome are unsoundly based.

38. Dr Peacock when challenged about his diagnosis, accepted that the initial test results did not confirm his diagnosis. He accepted that further tests may confirm, or not, his further diagnosis. He said that one such test, namely another MRI scan, may be able to provide some assistance in a shorter time than other available tests. He noted that it would be necessary to administer a general anaesthetic, albeit for a relatively short period, to **Mohammed** to enable such a scan to be undertaken.

39. He said that his neurological colleagues were intending to administer a further electroencephalogram test ("EEG"). He said that the further EEG was to assist in the ongoing management of the seizures which **Mohammed** was having. I do not think that a further EEG will assist in determining a diagnosis.

40. I infer from everything which I was told that all of the members of the treating team are proceeding with their management and treatment of **Mohammed** on the basis of the working diagnosis. I was not told of any contrary view.

41. However, Dr Peacock said that he had a high degree of confidence in the working diagnosis of PDD which was caused by a mitochondrial defect. This confidence was based on the following:

    (1) The neurological findings which are observable on the MRI scan;

    (2) The fact that **Mohammed** has, notwithstanding his treatment to date, persisting raised lactate levels in his blood;

    (3) The combination of features in his clinical presentation; and

    (4) The course of his clinical condition. I note that this has been well observed and charted whilst ever **Mohammed** has been in hospital.

42. Dr Peacock also relied on two other matters, namely, that he could not identify any other possible cause of **Mohammed**'s clinical condition, and that, in his opinion, there was no other available clinical diagnosis.

43. Doctors Jacobe and Piggins deferred to Dr Peacock's expertise and his superior knowledge of **Mohammed**'s clinical condition. But I note that they did not challenge the correctness of the diagnosis, nor did they suggest that there was any reason to doubt its correctness.

44. On the material before me, I am well satisfied that Dr Peacock's diagnosis is correct. The making of a diagnosis in a complex case such as this one requires attention to be given to all available imaging and other test results, together with clinical observations, and against a background of expert knowledge, to determine a diagnosis which is most likely to be the correct one. It is often the case, and not unexpected, that one or more of the indicia, to which regard is had, do not point in the direction of the established diagnosis. This means that the doctors must pause to consider the relevance of, or impact of, this indication on their diagnosis. But it is not always the case that this tells against the diagnosis.

45. Here, Dr Peacock's opinion, is a thoughtful and a broad based one. He cannot find any other diagnosis which explains **Mohammed**'s condition. It is particularly important to note that he maintains his diagnosis after observation of **Mohammed**'s clinical course over a lengthy period. In other words, this is not a diagnosis which has been reached quickly on inadequate material. On the contrary, it is a considered one which has regard to and weighs up all of the relevant factors.

46. Although they question the degree of certainty with which Dr Peacock expresses his view, the applicants do not suggest that they have obtained, or else had access to, any contrary professional opinion.

47. I accept that it Dr Peacock's diagnosis of PDD is correct. I am abundantly satisfied that it is a reasonable one upon which to base an assessment of **Mohammed**'s prognosis and likely future clinical course.

MOHAMMED'S PROGNOSIS

48. Dr Peacock expressed the view that **Mohammed**'s prognosis was grim. There is no known cure for his PDD, which is, in **Mohammed**'s case, a very severe condition. It is a life limiting illness, by which I took him to mean that it was a fatal condition. He said that the natural course of the illness is to result in **Mohammed**'s death.

49. He said that **Mohammed**'s neurological deficits will not improve. There is no known way for the brain to replace or restore any neurological function which has been lost.

50. He said that the only effective treatment which could be provided would be palliative care - that is care which aims to alleviate **Mohammed**'s pain and distressing symptoms. It is clear, that he envisages that the delivery of any

such care would closely involve the applicants. **Mohammed** will need to remain in hospital for the care to be provided.

51. It is notoriously difficult to predict the length of remaining life for anyone with a terminal illness. However, when pressed by the Court for an expression of opinion in this area, Dr Peacock said that he thought **Mohammed** would survive for a matter of weeks or a perhaps some months. He said that he thought that the absolute maximum of his further life expectancy was 9 months. But he said he anticipated **Mohammed**'s death "*sooner rather than later*".

MECHANICAL VENTILATION

52. Mechanical ventilation is a procedure by which oxygen is delivered to the lungs of a patient through a tube. It bypasses the patient's own breathing system. Once intubated, a patient is connected to the electrically powered mechanical ventilation system. Adjustments can then be made to ensure that a consistent level of oxygen is delivered to the patient, and that when necessary that level can be increased or decreased, so as to ensure that the patient's blood oxygen level is kept at a clinically appropriate level.

53. The direct benefit to be gained by placing **Mohammed** onto a mechanical ventilator is that it is likely to alleviate his breathing difficulties and ensure that he receives sufficient oxygen to stay alive, depending upon the progression of his intercurrent conditions.

54. The process of mechanical ventilation is an invasive one. **Mohammed** would need to undergo a general anaesthetic. After that took effect, a tube would be passed through his nose, down his trachea (airway) to the lungs. The naso-gastric tube would likely in due course be replaced by a tube which enters through the mouth and not the nose. In some cases, mechanical ventilation can be maintained, particularly on a long-term basis through a tracheostomy tube, ie one which enters the windpipe through a surgically created incision in the neck. That is not presently proposed for **Mohammed**, but it

remains a possibility. After a successful intubation, then connections are made to the ventilator and it takes over the provision of the oxygen to the patient.

55. The passage of a tube into **Mohammed**'s airways will be likely to cause him pain and discomfort.

56. Whilst ever **Mohammed** is being mechanically ventilated, it is necessary for him to receive sedative drugs, and to be maintained in a sedated state. In order for this to occur, there must be a peripheral venous catheter inserted. The site at which such a catheter is inserted into one of **Mohammed**'s veins needs to be regularly changed. In some patients this change needs to be about once in each week. In other patients, it needs to be done more frequently. In such patients, the site may need to be changed every few hours, but most likely about once on each day. In light of his age and size, and his extensive intercurrent medical conditions, I am satisfied that it would be more likely that **Mohammed** would fall into that category of patients who require their cannula site to be moved at least once per day.

57. If a peripheral venous catheter cannot be successfully inserted and maintained, or else a stage is reached when there is no further site which is readily available for the catheter, then the doctors would need to insert a central venous line into one of the large central veins. This would certainly require sedation for **Mohammed**, and perhaps a general anaesthetic.

58. The insertion and resiting of a cannula is a process which will cause pain and discomfort for **Mohammed**.

59. There are other risks and potential disadvantages for **Mohammed** if he is to be mechanically ventilated. They include:

    (i) He will require to be regularly suctioned which is an uncomfortable and unpleasant procedure. I note that at the moment he is regularly suctioned;

    (ii) He may suffer an airway injury because even if inserted competently, injury to the airway may result;

    (iii) He is always at risk of a sudden obstruction to his airway, or else the dislodging of the tube. In either case, an emergency necessitating immediate attention would ensue;

    (iv) Mechanical ventilation carries with it the risk of barotrauma which lead to a pneumothorax;

    (v) Mechanical ventilation carries with it a real risk of chest infection and ventilator associated pneumonia; and

    (vi) In the longer term, ie in a matter of weeks, a risk exists that his diaphragm, and the other muscles used for breathing, will start to atrophy through lack of use, which may have the consequence that he could not be weaned off the mechanical ventilator.

60. There are obvious and identifiable benefits for **Mohammed** if he is successfully mechanically ventilated. These include:

    (1) His breathing will be able to be controlled effectively and efficiently with an adequate oxygen

supply to his body, and hence no further deterioration in his neurological condition ought occur;

(2) The fluid which is presently accumulating and leading to congestive cardiac failure and respiratory difficulties, ought be able, with the assistance of his current medication regime, to be removed from his body; and

(3) The removal of his present cardiac and respiratory difficulties ought improve his general clinical condition with, at least theoretically, an enhanced ability to cope with his intercurrent conditions.

61. There are other features of **Mohammed**'s current condition which will not be directly improved, or ameliorated by the introduction of mechanical ventilation. These include his current neurological state, and his PDD. Whether he has seizures or not, and whether they can be prevented or treated will not be affected. He will not regain his sight or hearing. His hypotonia will not improve. His delayed development will not be remedied. He will still need to be fed through a tube. Except perhaps for his diuretic medicine, if it is no longer required, his medication regime will be unchanged.

62. Thus a real question arises as to whether, in the context of the entirety of **Mohammed**'s clinical condition, the benefits of mechanical ventilation for him outweigh the risks to him associated with its use. Put differently, whether it is in the bet interests of **Mohammed** to be mechanically ventilated.

63. Before considering this question, it is necessary to identify a number of matters which were mentioned and discussed in the course of the hearing but which I regard as being irrelevant to a proper consideration of the issues posed by the application.

CONSIDERATIONS NOT TAKEN INTO ACCOUNT

64. It was not suggested by the hospital that there was any financial reason, or any reason relating to a shortage of resources, beds or facilities which would preclude **Mohammed** being provided with mechanical ventilation if that was in his best interests. There may be occasions when such issues arise. If they do, there are undoubtedly complex questions of public health policy to be considered, and also whether, a Court is best fitted to engage in that area of discourse. Fortunately, in this case, this issue did not arise.

65. The applicants identified an adverse event which took place whilst **Mohammed** was an in-patient at the Hospital. They said that one of the consequences of this event was the deprivation of **Mohammed** of an adequate oxygen supply for a period of 10 to 15 minutes. The event took place in August 2012 in the Opthalmic Department. Dr Farrow acknowledged, on behalf of the Hospital, that this was a serious event which had been categorized in accordance with the NSW Health policy as a SAC 2 event. He said that the staff involved had been counselled. It is clear that the applicants attribute much of **Mohammed**'s neurological deterioration to this event.

66. It is not possible on the material before the Court to determine what was the outcome of this SAC 2 event on **Mohammed**'s clinical condition, nor what impact, if any, which it had. However, it is not necessary for the Court to be concerned with that question, because the orders which the Court is being asked to make, relate to **Mohammed**'s best interests as they are at the moment, and in so far as they can be predicted for the future. It is wholly irrelevant to this decision for the Court to consider whether any part of his disability arose because of the Hospital's conduct. It doesn't matter how his condition arose. What matters is to establish his present diagnosis, and his prognosis, and then to

consider what is in his best interests.

67. The third issue which occupied a small amount of time during the Court hearing was reference to, and use of, the phrase "*quality of life*". The phrase had been used prior to the Court hearing in discussions between the applicants and, at least, some of the doctors. According to the Macquarie Dictionary the phrase *"quality of life"* means

that enjoyment which can be got from living based on having sufficient physical and mental health to be able to participate in a meaningful way.

68. The applicants objected strongly to the use of the phrase with reference to **Mohammed**. I agree with their view. The definition set out above suggests as a minimum for the assessment of a quality of life that the person whose life is being assessed has a capacity to participate in life in a meaningful way.

69. But more importantly, as it seems to me, when applying that term to a 9 month old baby who does not yet talk or communicate verbally, and does not physically respond to anything other than painful stimuli, and cannot see or hear, identifying the integers which comprise an assessment of the baby's *"quality of life"* is impossible. Any such assessment necessarily reflects the individual values of the assessor.

70. In this case, I think that it is entirely unhelpful to engage in an ill-defined process which is quintessentially a subjective one for each assessor to determine what **Mohammed**'s quality of life is. I have not made any such assessment and I have disregarded as irrelevant, any expression of opinion by any of the doctors as to what **Mohammed**'s quality of life is or will be.

THE BEST INTERESTS OF MOHAMMED

The view of Mohammed's parents TS & DS

71. **Mohammed**'s parents argue that it is in his best interests to be placed on mechanical ventilation. They submit that his various clinical conditions can, and ought, be viewed separately. Hence they start with the proposition that because his respiratory function requires assistance, then all such assistance which is capable of assisting him to breathe ought be provided.

72. TS put, in the course of the hearing, to both Dr Peacock and Dr Jacobe, that if **Mohammed** was admitted to the Hospital with his current breathing difficulties as his only condition, then they would not hesitate to connect him to mechanical ventilation. They both agreed that such a course of action would be appropriate in the postulated circumstance. As well, they pointed to the fact that for a week or so at the end of June 2012, **Mohammed** had been successfully placed on, and then removed from, a mechanical ventilator.

73. The applicants went on to argue that since **Mohammed**'s breathing difficulties could be adequately addressed then they should be. They said that he would then have a chance to resist, or better cope with, his other illnesses. They concluded by expressing the view that **Mohammed** had survived for the whole of the 9 months of his life because he was "a fighter" and that he would, if given the chance, continue to fight for his health and life for as long as possible.

74. I entirely accept the genuineness and sincerity of the submissions of **Mohammed**'s parents. I accept that it is their view that **Mohammed**'s best interests are that he be placed on a ventilator.

The view of the doctors: Dr Peacock, Dr Jacobe & Dr Pigott

75. Although each of the doctors expressed their own view in different words, there was no difference in the substance of their opinions.

76. The doctors opined that it was in **Mohammed**'s best interests not to be subjected to the invasive procedure of mechanical ventilation with all which that entailed. Rather they said, having regard to the overall clinical picture, and his prognosis, **Mohammed**'s best interests were to be provided with pain relief and palliative care measures. They said that since his clinical condition was terminal, and that it was not possible to cure it, or alleviate it, other than, perhaps, temporarily by the use of the ventilator, the risks associated with mechanical ventilation, and the pain and distress caused by or associated with the procedure significantly outweighed any benefit which **Mohammed** would obtain from the ventilator.

77. In those circumstances, they said that it was not in his best interests to be put on a ventilator. Rather, it was in his best interests to receive pain relief and palliative care.

THE COURT'S JURISDICTION

78. The proceedings were brought in the exercise of the Court's *parens patriae* jurisdiction. This is an ancient prerogative jurisdiction with its origins likely to be found in the thirteenth century: *Re F (Mental Patient: Sterilization)* [1991] UKHL 1; [1990] 2 AC 1 at 26, 57; *Northridge v Central Sydney Area Health Service* [2000] NSWSC 1241; (2000) 50 NSWLR 549 at [16].

79. It cannot be doubted that the Court's jurisdiction is a broad one, deriving from the prerogative of the Crown to take care of a person who by virtue of a disability is unable to take care for themselves. Such a disability includes minority and mental incapacity: *Northridge* at [15].

80. As was said in *MAW v Western Sydney Area Health Service* [2000] NSWSC 358, (1999) 49 NSWLR 231 at [31]:

"The parens patriae jurisdiction of the Court is essentially protective in nature (*Marion's case* (at 280)) and although broad, is to be exercised cautiously: *J v C* [1969] UKHL 4; [1970] AC 668 at 695; *Marion's case* (at 280). Its existence and exercise are founded on a need to act on behalf of those who are in need of care and cannot act for themselves. In exercising its parens patriae jurisdiction the paramount consideration is the promotion of the health or welfare of the subject of the exercise of the jurisdiction. Its exercise should not be for the benefit of others: *Re Eve* (1987) 31 DLR (4th) 1 at 34. Furthermore, it has limits."

81. In *Re B (A Minor) (Wardship: Sterilization)* [1988] 1 AC 199, the Lord Chancellor, Lord Hailsham said at 202:

"There is no doubt that, in the exercise of its wardship jurisdiction the first and paramount consideration is the well being, welfare, or interests (each expression occasionally used, but each, for this purpose, synonymous) of the human being concerned, that is the ward herself or himself. In this case I believe it to be the only consideration involved. In particular there is no issue of public policy other than the application of the above principle which can conceivably be taken into account, least of all (since the opposite appears to have been considered in some quarters) any question of eugenics."

82. The nature of the problem with which this Court is confronted is not new. The Master of the Rolls described it in this way in *Re C (a minor) (Wardship: Medical Treatment)* [1989] 2 All ER 782 at 783:

"Turning now to the substance of the appeal, I have, most regretfully, to start with one fundamental and inescapable fact. Baby C is dying and nothing that the court can do, nothing that the doctors can do and nothing known to medical science can alter that fact.

The problem of how to treat the terminally ill is as old as life itself. Doctors and nurses have to confront it frequently, but it is never easy. Parents and relatives have to confront it less often and that makes it all the more difficult for them. Judges are occasionally faced with it when terminally ill children are wards of court. It is an awesome responsibility only made easier for them than for parents to the extent that judges are able to approach it with greater detachment and less emotional involvement."

83. One other matter is of particular importance in this case which is the nature of the doctor patient relationship. That arises because **Mohammed**'s treating doctors all express their strong view that the provision of mechanical ventilation is not in **Mohammed**'s best interests. So if the Court was to uphold the application, it would, in substance, be intruding into the doctor patient relationship by requiring the treating doctors to do something which they consider would be contrary to their professional obligation.

84. The relationship between a doctor and a patient may arise from a contract. It may arise in other circumstances, such as here where **Mohammed** is patient of a public hospital under a national health scheme. For present purposes, how the relationship arises can be put to one side. What is important, is the content of the obligation owed by a doctor to a patient. In *Breen v Williams* [1996] HCA 57; (1996) 186 CLR 71, Dawson & Toohey JJ said at [21]:

"A doctor is bound to exercise reasonable skill and care in treating and advising a patient, but in doing so is acting, not as a representative of the patient, but simply in the exercise of his or her professional responsibilities. No doubt the patient places trust and confidence in the doctor, but it is not because the doctor acts on behalf of the patient; it is because the patient is entitled to expect the observance of professional standards by the doctor in matters of treatment and advice and is afforded remedies in contract and tort if those standards are not observed and the patient suffers damage."

85. In *Rogers v Whittaker* [1992] HCA 58; (1992) 175 CLR 479, Mason CJ, Brennan, Dawson, Toohey and McHugh JJ said at :

"The law imposes on a medical practitioner a duty to exercise reasonable care and skill in the provision of professional advice and treatment. That duty is a "single comprehensive duty covering all the ways in which a doctor is called upon to exercise his skill and judgment" (*Sidaway v. Governors of Bethlem Royal Hospital* [1985] UKHL 1; (1985) AC 871, per Lord Diplock at p 893); it extends to the examination, diagnosis and treatment of the patient and the provision of information in an appropriate case (*Gover v. South Australia* (1985) 39 SASR 543, at p 551.). It is of course necessary to give content to the duty in the given case.

The standard of reasonable care and skill required is that of the ordinary skilled person exercising and professing to have that special skill (*Bolam v. Friern Hospital Management Committee* (1957) 1 WLR 582, at p 586; see also *Whitehouse v. Jordan* [1980] UKHL 12; (1981) 1 WLR 246, per Lord Edmund-Davies at p 258 and *Maynard v. West Midlands R.H.A* (1984) 1 WLR 634, per Lord Scarman at p 638)..."

86. What is being sought from the Court in this application is that in the exercise of its *parens patriae* jurisdiction, it has the responsibility to order the doctors to do something which they in the exercise of their professional judgment do not wish to do. This necessarily intrudes into their professional obligations, it seeks to dictate to them how they must perform those obligations. Lord Donaldson MR considered a like situation in *Re J (a Minor)(Wardship: Medical Treatment)* [1990] 3 All ER 930. He said at 934:

"Before considering these submissions, it is sensible to define the relationship between the court, the doctors, the child and its parents.

The doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion (see *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118, [1957] 1 WLR 582). This duty is, however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive treatment.

The parents owe the child a duty to give or to withhold consent in the best interests of the child and without regard to their own interests.

The court when exercising the parens patriae jurisdiction takes over the rights and duties of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or to withhold consent is that of the court alone.

It follows from this that a child who is a ward of court should be treated medically in exactly the same way as one who is not, the only difference being that the doctors will be looking to the court rather than to the parents for any necessary consents.

No one can dictate the treatment to be given to the child, neither court, parents nor doctors. There are checks and balances. The doctors can recommend treatment A in preference to treatment B. They can also refuse to adopt treatment C on the grounds that it is medically contra-indicated or for some other reason is a treatment which they could not conscientiously administer. The court or parents for their part can refuse to consent to treatment A or B or both, but cannot insist on treatment C. The inevitable and desirable result is that choice of treatment is in some measure a joint decision of the doctors and the court or parents.

This co-operation is reinforced by another consideration. Doctors nowadays recognise that their function is not a limited technical one of repairing or servicing a body. They are treating people in a real life context. This at once enhances the contribution which the court or parents can make towards reaching the best possible decision in all the circumstances."

87. Although the Master of the Rolls was there considering a matter involving a ward of the Court, no different principle applies in this case where the Court is being asked to exercise its *parens patriae* jurisdiction.

DISCERNMENT

88. Two questions arise. First, is it in the best interests of **Mohammed** for him to have treatment by way of mechanical ventilation. Secondly, if it is, can and should the Court order that, contrary to the views of his treating doctors, mechanical ventilation must be provided.

89. I do not think that it is in the best interests of **Mohammed** for him to be mechanically ventilated.

The risks which I have earlier enumerated cannot be ignored. The procedure will cause **Mohammed** pain and discomfort. At best he will receive a temporary benefit. But it will not cure his condition, nor will it play any role in alleviating his outcome.

90. **Mohammed**'s life is to be measured in the short term. He should not be subjected to pain and discomfort for the remainder of his life by being placed on mechanical ventilation from which he will not be weaned. It is for these reasons that I agree with the expert opinions of **Mohammed**'s doctors that it would be better for him to be treated by pain relief and palliative care than by the invasive procedure of mechanical ventilation. That is what is in his best interests.

91. This conclusion is sufficient to warrant a rejection of the parents' application.

92. However, it is appropriate that I venture an answer to the second question which I have posed. In the exercise of the Court's *parens patriae* jurisdiction, it will be a rare occasion when a court by a mandatory order interferes in a doctor/patient relationship in a way which compels the doctors to do something which they regard as contrary to their patient's best interests.

93. If the court is satisfied that the opinions of the doctors have been reached after careful consideration having regard to the correct and relevant matters and are opinions reached in the proper exercise of their professional judgment as to what is in the best interests of their patient, then I very much doubt that a court would ever make an order of the kind sought here. That is because it is not the role of the court to interfere in such a professional relationship and to compel action by an unwilling participant which would have the consequence of placing that individual in the position, in good conscience, of choosing between compliance with a court order and compliance with their professional obligations.

94. Here, I am well satisfied that the doctors' opinions as to **Mohammed**'s best interests have been reached conscientiously and in the proper discharge of their professional obligations. They have no doubt of their opinions, they have no doubt as to what is in the best interests of **Mohammed**. As it happens, I agree with them. But regardless of my opinion, I would not have been prepared as a matter of discretion to order them to do something with which they did not agree.

95. On this basis, as well as the first basis which I have discussed, I decline to make the orders which the parents seek.

CONCLUSION

96. The present case is one of the saddest which can be imagined. The court is concerned with a young baby who has become terminally ill in circumstances which cannot be fully explained. But the court's responsibility is to assess what is in **Mohammed**'s best interests and not to allow its judgment to be swayed by sympathy, and the attractive ease of requiring the medical practitioners to provide mechanical ventilation for **Mohammed**.

ORDERS

97. I make the following orders:

    (1) Application dismissed.

(2) I discharge the interlocutory order of the court made on 21 December 2012.

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