H399

High Court of Ireland Decisions

Judgment

Title:	Health Service Executive -v- J.M. A Ward of Court & ors
Neutral Citation:	[2017] IEHC 399
Date of Delivery:	22/06/2017
Court:	High Court
Judgment by:	Kelly P.
Status:	Approved

THE HIGH COURT

[WOC 8887]

IN THE MATTER OF J.M. A WARD OF COURT

BETWEEN

HEALTH SERVICE EXECUTIVE

APPLICANT

AND

J.M. A WARD OF COURT

RESPONDENT

AND

G.M. AND M.M.

NOTICE PARTIES

JUDGMENT of Mr. Justice Kelly, President of the High Court delivered

on 22nd day of June, 2017

Restrictions

1. This case concerns a ward of court (J.M.). It is subject to reporting restrictions. Although the case was heard and judgment is being delivered in open court it is subject to an order which I made pursuant to the provisions of s.27 of the Civil Law (Miscellaneous) Provisions Act 2008. That prohibits the publication or broadcast of any matter relating to these proceedings which would, or would be likely to identify the ward of court as a person having a medical condition. With a view to ensuring compliance with that section the identities of the various parties and witnesses have been anonymised and they are referred to by initials only.

Background summary

2. J.M. is 36 years of age. He was admitted to hospital A in July 2012 with *haematemesis* (gastro-intestinal bleeding). He has never left the hospital since that date. His condition worsened and he is now and has been for a number of years a patient in the High Dependency Unit of the hospital.

3. J.M. is in what is called a minimally conscious state (MCS). All of the expert witnesses agree on this. Because of that he lacks capacity to make decisions for himself. He cannot speak.

4. The first notice party G.M. is J.M.'s father. The second notice party M.M. is his mother.

5. After much discussion with, and explanation to, J.M.'s parents the hospital authorities sought their consent to the withholding of an increase in existing ventilator support in the event of him suffering a respiratory deterioration. They also sought consent that, in the event of his clinical deterioration, they might withhold vasopressor support, cardiopulmonary resuscitation (CPR), cardioversion, defibrillation and the insertion of arterial or central venous lines for monitoring of cardiovascular variables. Such consents were not forthcoming. Absent such consent the applicant sought to have J.M. made a ward of court. I made that order on 18th July, 2016. His parents were appointed as his Committee. On that occasion I gave liberty to the applicant to issue the motion which is before the court and gave directions concerning an exchange of affidavits. I also directed the applicant to commission and circulate reports from experts nominated by J.M.'s parents to advise them in relation to his condition. These experts gave evidence before me as did a number of other doctors from different disciplines. They included consultant anaesthetists, a consultant neurologist and a consultant in respiratory medicine.

6. Having heard all of the evidence and before final submissions were made to me I visited J.M. in hospital A. I observed him in bed in the High Dependency Unit. I was accompanied by his mother, Dr. M., a consultant anaesthetist on the staff of the hospital and a nurse from the unit. I spent about fifteen minutes in his presence and witnessed his mother and the doctor speak to him and give him some instructions and I observed his response thereto.

7. The applicant seeks a twofold order from the court in the same terms as the consent which was sought from J.M's parents.

What the case is not about

8. It is important to state what this case is ***not*** about. It is not about the switching off of a life support machine. It is not about the withdrawal of hydration or nutrition. It is not about the withdrawal of antibiotic or antimicrobial therapy. It is not about withdrawing any of the supports which J.M. has at present. Rather, it is an application which is made in anticipation of the possibility of J.M. suffering either a respiratory or clinical deterioration. Should either or both of those events happen, the court is asked to make an order which would permit, but not compel, J.M.'s treating doctors, in the exercise of their clinical judgment, to withhold an increase in his existing ventilator support in the event of a respiratory deterioration and to withhold CPR and the other procedures identified in the event of a clinical deterioration.

9. The case is also not one where I am called upon to make any determination concerning the cause of J.M.'s unfortunate condition and still less whether anyone bears a legal liability for such condition.

Medical history

10. J.M. was born on 8th December, 1980. He weighed just 2 lbs. 10 ozs. at birth having been born, according to his mother, some three months prematurely. He grew up with his parents and one brother who is a few years younger than him. He sat for his Junior Certificate examination in 1996 and obtained four honours. He did not have a happy time in school thereafter apparently as a result of bullying. He was referred to a psychologist and ultimately to a psychiatrist and has been interacting with the psychiatric services since then. Immediately prior to the events of July 2012 he was living in a community residence and was being treated for his psychiatric difficulties in the community.

11. In 2011 he suffered a head trauma with a loss of consciousness, as a result of which a CT scan of his brain was carried out on 4th August, 2011. It raised the possibility of mild cerebral oedema. An MRI brain scan on 12th

August, 2011 was normal as was a CT scan carried out on 13th September, 2011.

12. On 6th July, 2012 he presented to hospital B with *haematemesis.* He was immediately transferred to hospital A for continued resuscitation, intubation and an oesophago-gastro-duodenoscopy (ogd) which revealed severe gastritis, oesophagitis and duodenitis.

13. Subsequent to this procedure he had to be admitted to the intensive care unit for multi-organ support including dialysis.

14. Over the following three weeks J.M. underwent a number of level 2 therapies for hypoxaemia including high frequency oscillation ventilation, prone position ventilation and inhaled nitric oxide.

15. Thereafter there was an improvement in J.M.'s clinical condition and sedative medications were weaned. However, this was complicated because of an episode of self extubation which required re-intubation and another increase in ventilator supports on 8th August, 2012. Five days later he had a surgical tracheotomy. Four days later a toxic megacolon required a right hemicolectomy, ileostomy and mucous fistula.

16. J.M.'s post operative course was complicated because of a tension pneumothorax which needed a left chest drain to be sited on 19th August, 2012. He suffered septicaemia and sinusitis on 9th September, 2012. He also suffered from arm and leg deep venous thromboses but fortunately did not have a pulmonary embolism. Over the period of 10th and 11th September, 2012 J.M. was sedated. Thereafter he never regained power in his legs and left arm. His mother gave graphic evidence of her observation of the deterioration in his condition over these days and those immediately preceding them.

17. An MRI scan of his brain was ordered because of orofacial dyskinesia which revealed bilateral hyperdensities in the basal ganglia and white matter of the brain. Acute pallidal necrosis was noted when the scan was compared to that taken in 2011.

18. A working diagnosis of Wilson's disease was made but after multiple investigations a liver biopsy carried out on 6th June, 2014 was negative for that condition.

19. J.M. was seen by consultants of various descriptions including consultant neurologists. At one stage it was thought that he might have an underlying mitochondrial disorder. Tests were carried out including some which were

sent to the U.K. for analysis. Despite this it has not been possible to prove the existence of an underlying mitochondrial disorder conclusively.

20. A further MRI scan was carried out on 9th February, 2015 and revealed generalised brain volume loss.

21. His lead ICU physician is Dr. N. She is a consultant anaesthetist intensivist. She commenced work in hospital A in August 2014. Since January 2015 she has been the principal doctor responsible for his care. She gave evidence and impressed me as being deeply committed to the welfare of her patient, a view shared by J.M.'s parents. I was impressed not merely with her medical skill and knowledge but also by her candour and obvious empathy for her patient and his family. This latter quality is perhaps best exemplified by an answer which she gave in cross-examination on the second day of the hearing.

> *"I understand what this family feels, believe me, this family has had a terrible time. This family's son is in a terrible condition, he has had a terrible outcome and I am extremely sorry that this happened in hospital A and that is why I am here today instead of working in the maternity hospital."*

22. Dr. N. has concluded that J. M. has a severe, non-traumatic, multi-factorial irreversible brain injury. Her views in that regard are shared by Dr. C. who is the treating consultant neurologist. None of the medical personnel who gave evidence before me disagree with this diagnosis. It is not known how this occurred.

Summary of J.M.'s current medical condition and diagnosis

23. J.M. is unable to speak. He cannot feed himself. He is tube fed. He cannot walk. He is only able to move his right upper limb and when he does so it is in an uncoordinated fashion. He breathes through a tracheostomy. He needs high level nursing support at all times.

24. Dr. N. has diagnosed him as being in a MCS. This is a view which is shared by Mr. M. a senior clinical neuro-psychologist who carried out extensive testing on J.M. Mr. M. is not attached to hospital A or B. This diagnosis was not disputed by any of the doctors who gave evidence.

25. Dr. C., the treating consultant neurologist, gave evidence that there has been significant brain volume loss which is apparent when one considers the MRI brain scan carried out in 2012 with one which was carried out in February 2015. That volume loss shows that there has been some degree of atrophy which was described by the doctor as a negative event.

26. According to Mr. M., J.M. has cognitive impairments, disorders of consciousness with fluctuating levels of awareness and possible sensory impairments. Both Dr. M. and Mr. M. were firmly of the view that the ward does not suffer from what is called "locked-in syndrome".

27. The above diagnoses and views are not dissented from by either Dr. McE., a consultant in physical and rehabilitation medicine who did not give evidence but whose reports were placed before the court, or by Professor B., who is a consultant respiratory physician who gave evidence. Thus there is unanimity as to J.M.'s diagnosis and condition.

Setbacks

28. Between July 2015 and July 2016 J.M. had three setbacks which were described as "major clinical deteriorations". One of these deteriorations was an arrhythmia which responded to medical therapy (Beta-blockade). Had that medical treatment not worked, other treatment such as CPR would have had to be administered. Should such an event occur in the future the applicant seeks to be dispensed from having to provide such alternative treatments.

29. The other two setbacks were respiratory tract infections. They were treated with increased ventilatory support and antibiotics. In the event of such recurring, the treating doctors seek to be relieved from the necessity of increasing ventilator support. They would, however, administer antibiotics as appropriate. They would also continue to perform regular tracheostomy changes, urinary catheter changes and stoma wound care. If J.M. did not respond to fluids and antibiotics during an episode of respiratory sepsis then the focus of his care would be on ensuring that he avoids distress. So, if his breathing were to become laboured, he would be given a subcutaneous infusion of morphine in a syringe driver and it would include medications to reduce the production of respiratory secretions.

30. The treatments given to J.M. during these two episodes were successful. Indeed it is to the credit of the medical and nursing staff that he has had no major setback of this type since July 2016. Patients in his compromised position are notoriously prone to infection and it is a tribute to the care that he has received that he has not contracted any infections recently.

31. It is because of the prospect of such a setback recurring in future that this application has been brought.

MCS

32. I have found the Working Party Report from the Royal College of Physicians on *Prolonged Disorders of Consciousness* to which I have been referred, together with the medical and psychological evidence which was

tendered to be of considerable assistance in obtaining an understanding of MCS.

33. Before going further I should sound a note of caution about the term MCS which has the capacity to mislead. This possibility has been identified by both Baker J. and Peter Jackson J. in England and their observations were referred to by Baroness Hale in delivering her judgment in *Aintree University Hospitals NHS Foundation Trust v. James & Others* [2013] UKSC 67 where she said:-

> *"But, as Baker J. has pointed out in In Re M. [Adult Patient] (Minimally Conscious State: Withdrawal of Treatment) 2011 EWHC 'there is a spectrum of minimal consciousness extending from patients who are only just above the vegetative state to those who are bordering on full consciousness.' Peter Jackson J. added [2012] EWHC 3524 that:- 'to that extent the word "minimal" in the diagnostic label may mislead'."*

Thus the term MCS has to be used with caution.

34. The working paper points out that:-

> *"Consciousness is an ambiguous term, encompassing both wakefulness and awareness.*
>
> *o 'Wakefulness' is a state in which the eyes are open and there is a degree of motor arousal; it contrasts with sleep - a state of eye closure and motor quiescence,*
>
> *o 'Awareness' is the ability to have, and the having of, experience of any kind.*
>
> *There is no simple, single clinical sign or laboratory test of awareness. Its presence must be deduced from a range of behaviours which indicate that an individual can perceive self and surroundings, frame intentions and interact with others."*

35. The working paper, in dealing with the definitions of disorders of consciousness identifies three, all of which are quite distinct from "locked-in syndrome" or "brain stem death". The locked-in syndrome is stated to "*usually result from brain stem pathology which disrupts the voluntary control of movements without abolishing either wakefulness or awareness. Patients who are "locked-in" are substantially paralysed but conscious, and can usually communicate using movements of the eyes or eyelids*." J.M. is not suffering from this condition and cannot communicate.

36. Brain stem death implies the loss of all brain stem functions, as confirmed by the absence of brain stem reflexes and spontaneous respiratory effort in response to rising carbon dioxide levels. J.M. is not in this condition.

37. The three disorders of consciousness which are referred to in the working paper are coma, vegetative state (VS) and MCS. He manifestly is not in a state of coma since that is defined as a state of unrousable unresponsiveness.

38. VS is defined as:-

> *"A state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviour. VS is characterised by complete absence of behavioural evidence for self or environmental awareness.*
>
> MCS is defined as:-
>
> *"A state of severely altered consciousness in which minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated. MCS is characterised by inconsistent, but reproducible responses above the level of spontaneous or reflexive behaviour, which indicates some degree of interaction with their surroundings."*

39. The working paper makes it clear that the definition of MCS was first published as recently as 2002. That publication was by the Aspen Neurobehavioral Conference Workgroup. It was based on the requirement for at least one clear cut behavioural sign of consciousness indicating that patients retain at least some capacity for cognitive processing. In order to make a diagnosis of MCS, limited, but clearly discernible evidence of self or environmental awareness must be demonstrated on an inconsistent but reducible or sustained basis, by one or more of a series of behaviours which are listed in the working paper. Four are specified. They are:-

> 1. Following simple commands,
>
> 2.Gestural or verbal "Yes/No" responses (regardless of inaccuracy),
>
> 3. Intelligible verbalisation, and
>
> 4. Purposeful or discriminating behaviour including movements or affective behaviours that occur in contingent relation to relevant

environmental stimuli and are not due to reflexive activity.

40. On the evidence that I have heard J.M. exhibits just one of those behaviours. There is evidence of him following simple commands. None of the others have been evident.

The psychological assessment

41. Mr. M. is a clinical neuropsychologist who specialises in working with patients who have had defined brain injuries or neurological conditions that would affect their level of ability to function and communicate. He prepared two reports for the purposes of this litigation and gave extensive oral evidence before me. His view was formed not merely by a consideration of his own examination of J.M. together with a consideration of all of the relevant medical and nursing material but also by reviewing a series of videos and score sheets completed by the staff who looked after J.M. over a period of two weeks. The personnel who participated in that exercise are to be complimented for the additional work which they undertook in an effort to ensure that Mr. M. was able to form as comprehensive a picture of J.M.'s condition as possible.

42. Mr. M. reviewed 30 such videos together with the score sheets. They were prepared by members of the staff familiar with J.M. thus improving the reliability of the scores awarded.

43. Before considering the videos and the score sheets, Mr. M. had formed the view that J.M. was functioning in a MCS. He said that J.M. appeared to be aware of activities within his environment but might not respond immediately. He required adequate time to reach a level of arousal but his level of processing appeared to indicate that he perceived acoustic and phonological commands. Having had the benefit of the additional material Mr. M. was of no different opinion. He said in his report:-

> *"In reviewing the overall assessment and the comments regarding the limitations of the assessment the examiner would state that J.M. has demonstrated consistently that he has responded to stimuli on an inconsistent nature. (sic) Nonetheless he still responded to stimuli on a basis that would lead an objective assessor to an opinion that he is aware to some extent of his surroundings. His level of awareness is fluctuating and is compromised by his -*
>
> *o Physical functions*
>
> *o Cognitive impairments*

o Possible sensory impairments

o Fatigue

o Level of arousal

o Latency of response

The examiner would suggest that J.M. is still best described as functioning in a MCS.

The examiner would state, however, that after four years, it is unlikely that J.M.'s level of cognitive ability or cognitive arousal is likely to increase any further than is currently present.

Outside of his physical status and the necessary medical or nursing requirements, the examiner would suggest that a similar environment where interactions can take place on a one to one level would be at the optimal level for J.M. Should his physical status or his medical condition allow him to be transferred to a rehabilitation facility and/or a nursing home, this in the examiner's view would be an environment where an individual having this type of cognitive functioning are (sic) typically cared for. In these environments a programme of both appropriate rehabilitation and/or activation or cognitive simulation could be designed to ensure appropriate interaction and stimulation."

44. None of the medical personnel dissent from the views expressed by Mr. M. My own observation of J.M. satisfied me that he did appear to have an ability to follow a simple command such as "open your eyes" after a considerable period of latency, *i.e*., delay between the command being given and the response.

45. Having regard to the uncontroverted views that have been expressed I have no difficulty in accepting that J.M. is indeed in a MCS. Of the four behaviours identified in the working paper the only one that he has demonstrated is the ability to follow simple commands. His level of consciousness is limited as described by Mr. M. Thus, although he is above the level of a VS he is very far from "bordering on full consciousness".

Pain

46. Obviously the question of whether J.M. can experience pain is a matter of great concern. Again I have found the working party report coupled with the medical and psychological evidence which I have heard to be very helpful on this topic.

47. The working party report says:-

> *"Patients in PVS are believed to lack any capacity to experience the environment, internal or external, but complete certainty that primal sensations, such as pain, are absent is impossible to know. Patients in MCS, on the other hand, are likely to experience pain but may not exhibit the behaviours that are usually seen in people with pain."*

In dealing with the topic of "the evidence on pain" the working party reports:-

> *"Researchers have investigated pain experience through the use of PET scans and functional connectivity analysis in patients with PDOC compared with normal controls. Preliminary findings in a very small sample suggests the following:*
>
> *• In VS patients, although painful stimuli reached the primary somatosensory cortex (the area of the brain that "senses" pain and coordinates reflex responses) they do not reach the higher order associative cortices (those areas that are responsible for perception and awareness of pain).*
>
> *• By contrast, MCS patients showed a close to normal pattern of neural activation, suggesting that the ability to experience pain, and presumably other symptoms, is probably unimpaired.*
>
> *• Neuroimaging studies also suggest the possibility of emotional response and processing, as well as pain in a minority of patients with MCS. Therefore, the potential for continuing mental distress is of equal concern.*
>
> *Whilst not provable, this offers plausible, empirical reasons to suggest that living in a minimally conscious state with some level of awareness could, in some circumstances, be a worse experience than living in a vegetative state with no awareness.*
>
> *Clinicians are therefore urged to pay careful attention to the prevention, management and monitoring of pain and discomfort for patients with PDOC. For example, the identification of a painful condition (such as a dental abscess or ingrowing toenail) should lead not only to the prescription of analgesia, but to treatment for the underlying problem. However, pain symptoms that accompany neurological disability (as described above) will not always be avoidable.*

> *These factors should also be borne in mind when weighing up the balance of benefits and harms to inform best interests decisions relating to treatments that are given to prolong life."*

48. Later in the paper it is said:

> *"Life prolonging care may therefore have negative value for patients who experience some minimal awareness, but have little to no hope of further recovery and little prospect of escaping a condition that is unacceptably burdensome and inconsistent with the values and beliefs they held before injury. For these reasons the best interests decision making in respect of someone in MCS is particularly complex and often finely balanced."*

49. Dr. M. gave evidence that she has seen J.M. in "*very severe dystonia which has looked very painful to me*". Dr. N. in her evidence relied upon the extracts from the working party paper which I have quoted and agreed with the conclusions that a person in a MCS can feel pain. Mr. M. in giving evidence on this topic was asked the following question by me: "*So, you would be fairly certain that he can experience pain*?" Answer "*I think that's a little bit strong, Your Honour, I'm not sure. I think it is a reasonable proposition that he may experience pain*."

50. Dr. M2 (who was described by Dr. N. as "*the foremost authority on intensive care in Ireland*") on being asked his opinion as to the likelihood that the escalation of resuscitation would be accompanied by pain or distress for J.M. said:

> *"Yes, I think when one is defined as having a minimally conscious state there is a presumption therefore of a degree of awareness and where there is a presumption of a degree of awareness, one must presume the potential for pain, distress, discomfort, anxiety, fear, it is very difficult to measure but the presumption is there. Some of the reference documents submitted by Dr. N. in her affidavit, the Royal College of Physicians document, is very clear on this point. There are a number of documents I would be happy to reference should you wish."*

The witness then submitted the *Australian and New Zealand Intensive Care Society Statement on Care and Decision-Making at the End of Life for the Critically Ill* dated 2014.

51. All of this evidence leads me to believe that the probability is that J.M. can feel pain and I so find.

Awareness

52. The persons who know J.M. best are, of course, his parents. Both of them gave evidence.

53. Both parents are deeply committed to him and are now and have been throughout his lengthy hospitalisation regular visitors. Naturally they wish their son to live. They found themselves unable to give the consent that was sought by the hospital authorities, hence this application. Mr. M. told me that he could not have it on his conscience to give the consent in question.

54. Both believe that they witnessed their son demonstrating awareness and enjoyment of their presence. His mother said that when she and her husband speak to him he turns his head towards them. He has an interest in GAA and will look up at the television when matches are being broadcast. They believe he has developed an interest in a country music singer called Nathan Carter. His music, they believe, calms him and he seems to like it. Evidence was given of him responding to a command to give a "thumbs up" sign. I witnessed his response to such a command both on the video evidence that was put before me and indeed on my own visit to the hospital. I observed a very weak, delayed and minor movement of the thumb in response to such a command. There is a particular priest, a Fr. Eamonn, who visits and talks to J.M. a lot about football, hurling and soccer. He responds well to him and on one occasion would not open his eyes during his presence. When he was told that the priest had gone and he was told he could open his eyes he did so. As his mother said: "*It's hard to believe that he don't know what's going on*".

55. I am prepared to accept that his level of consciousness is such as to on occasion give him an awareness of the presence of persons and some ability to enjoy the company of those with whom he is familiar as well as music or television sports broadcasts. By the same token, adopting Dr. M2's approach, one ought to presume the potential for distress, discomfort, anxiety and fear.

J.M.'s prognosis

56. J.M.'s condition is disimproving with time. This was the view of Dr. N., Dr. M. and Dr. C. It is a view which is supported by the report of the working party. I refer to that part of the report which is at p.9 under the heading "Prognosis for Recovery". The report states:

> *o "For both vegetative state and minimally conscious state, the likelihood of significant functional improvement diminishes over time.*

o The cause of brain injury is a strong determinant to outcome for both vegetative state and minimally conscious state. Patients with non traumatic (e.g. anoxic brain or other diffuse) injury have a shorter window for recovery and greater long term severity of disability than patients with traumatic injury…

o The prognosis for recovery is more heterogeneous for minimally conscious states than for vegetative states, although age and level of awareness may have some predictive value.

o The majority (in excess of 60 - 72%) of reported cases of patients who have emerged from MCS have done so by two years after injury, with a further 30% emerging at 2-4 years. Cases of MCS patients emerging after more than five years from injury have rarely been reported.

o In both vegetative state and minimally conscious state, there are isolated reports of recovery of consistent consciousness even after many years, but these are a rarity, and inevitably those who recover remain profoundly disabled."

57. J.M. suffered a non-traumatic brain injury and so has a "shorter window for recovery and greater long term severity of disability" than a patient with a traumatic injury. The view of Professor B. is that J.M.'s prognosis is very poor. The likelihood is that J.M., according to him, will probably succumb to a respiratory infection somewhat similar to those that occurred on two occasions to date.

58. There is sadly no realistic prospect of any improvement in J.M.'s condition. He is likely to continue to disimprove.

The orders sought - medical evidence

59. The orders sought envisage two distinct possibilities each involving a deterioration in J.M.'s condition. In the case of a respiratory deterioration authority is sought to withhold an increase in existing ventilator support. In the case of a clinical deterioration, authority is sought to withhold CPR and the other therapies identified. Both of these orders are sought in the best interests of the ward.

60. Some of the extensive medical evidence can be regarded as common to both orders sought. Other aspects of it are specific to each order.

61. There is virtually no dispute on the medical evidence generally or in respect of the specific reliefs sought regardless of the particular discipline of the witness or by whom the testimony was adduced.

Evidence common to both reliefs

62. I will deal first with the medical evidence which is common to both reliefs.

63. Dr. M. was asked on the first day of the hearing:-

> Question: "*In the event of a crisis or a sepsis or deterioration of a very significant kind, in your view is it clinically justified to increase the level of intervention by way of resuscitation or CPR?*"
>
> Answer: "*No*".
>
> Question: "*Why do you say that*?"
>
> Answer: "*I say that because J.M. has been now in our intensive care unit and in our critical care area since 2012. He has shown no neurological improvement. He has had repeated and aggressive ongoing care and I don't believe it is in his best interests and I don't truly believe it's fair*."

Dr. N. on the same day was asked:

> Question: "*You formed a view, as you say, in paragraph 10 of your affidavit, that 'repeated full ventilation and other resuscitation measures will only prolong J.M.'s suffering' - is that still your view*?"
>
> Answer: "*That is still my view*."
>
> Question: "*And you said that at the time you shared your opinions and discussed them with both Professor C. and Dr. C. and that they agreed with your opinion; is that right*?"
>
> Answer: "*That is true*."

64. Professor B. who was one of the experts retained by J.M.'S parents said in response to question put by me as follows:

> Question: "*Could I just ask you two questions, both by reference to the notice of motion and the reliefs that are sought at numbers 2 and 3. Do I correctly gather from your evidence that it is your professional opinion as a consultant respiratory physician that in the event of J.M. having a respiratory deterioration that it is not in his best interests that he should have any increase in ventilator support*?"

Answer: "*Yes is the answer to that Judge*."

Question: "*The ultimate decision being with the lead medical physician insofar as that decision is concerned*?"

Answer: "*Yes*."

Question: "*If it were your decision and you were the lead medical physician you would not increase the existing ventilator support in the event of him having a respiratory deterioration*?"

Answer: "*No, I would not, but I would be very disappointed with myself if I couldn't bring a family on board to that, but if I couldn't so be it, I would have to make the decision*."

Question: "*My second question then is by reference to paragraph 3, it is again on the basis of your experience as a consultant respiratory physician, in the event of a clinical deterioration occurring in J.M. do you believe that it would be in his best interests that vasopressor support should be withheld*?"

Answer: "*I do believe that it would be in his best interests that they should be withheld*."

Question: "*Likewise do you take the same view in relation to cardiopulmonary resuscitation*?"

Answer: "*Yes*."

Question: "*Did you take the same view in relation to cardioversion*?"

Answer: "*Yes. On balance yes*."

Question: "*Do you take the same view in relation to defibrillation*?"

Answer: "*On balance, yes*."

Question: "*And insofar as there might be considered the insertion of arterial or central venous lines for the monitoring of cardiovascular variables would you take the view that that would not be in his best interests either*?"

Answer: "*I would take that view*."

Question: "*Again in this case, as in the case of No. 2, the ultimate decision being with of course the lead physician*?"

Answer: "*Yes.*"

Question: "*If you were the lead physician they would be your views. You would not do either of the things that are identified in paragraphs 2 or 3*?"

Answer: "*I would be extraordinarily reluctant not to do them if I did not have the family on board but in that unhappy circumstance I would not do them*."

65. Dr. M2 said this in relation to both orders sought.

"With regard to the limitations and escalation of therapies defined in paragraphs 2 and 3 of the notice of motion, this might be best considered both in terms of non-beneficial therapies and the potential to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring. This is most likely to arise in the context of a new sepsis, particularly respiratory. J.M. has suffered repeated episodes of respiratory sepsis, treated with antimicrobials and it is my understanding that his doctors intend to continue to treat with antimicrobials as required. It is my opinion that escalation of therapies beyond this to require intensive care is most likely non-beneficial in the overall context of his underlying condition. Intensive care places a burden on the patient, with many therapies being potentially distressing. Such therapies should therefore be instituted if for the overall benefit of the patient. Where non-beneficial, therapies should focus on his comfort and dignity. The opinion therefore is summarised as 'my opinion with regard to J.M. is that escalation of therapies is more likely non-beneficial potentially distressing and therefore inappropriate'."

This latter view was also shared by Dr. N.

66. Professor B. in dealing with the chances of a successful resuscitation said:-

"The chances of a successful resuscitation are vanishingly rare and even if the resuscitation in the narrow sense of the word "resuscitation" were successful, it is extremely unlikely that the patient would not have a much more impaired quality of life afterwards than before. As I said in my report, the resuscitation does involve trauma, it does involve significant risks even in the

best of hands and if I were the lead clinician here, I would, in the American sense of the word, try to embrace the family and come to an agreed conclusion that in all the circumstances here, that full resuscitation would not be in the patient's best interests in the short or the long term."

67. Finally, on this aspect of both orders I asked questions of both treating physicians, Dr. N. and Dr. M. of the position which would obtain if these orders were refused. This is my exchange with Dr. N.

> Question: "*If I were to refuse that order so that consent would not be forthcoming for you to withhold an increase in existing ventilator support and the other reliefs that are sought at paragraph 3, would that create ethical difficulties for you*?"
>
> Answer: "*It creates ethical difficulties, but I also see myself as an employee. I now have a line manager as in the Chief Clinical Director. Some of my senior colleagues, actually, their contracts are such that they don't have that same line manager. As an employee, I would, I think, need to listen to my line manager. So while it would create ethical difficulties for me, I think it would be necessary for me to respect the order of the court*."
>
> Question: "*Would it involve you behaving in a manner inconsistent with your medical judgment*?"
>
> Answer: "*Yes.*"
>
> Question: "*And would I correctly characterise it if you would feel under a sense of compulsion to do something which medically you believe not to be in the best interests of your patient*?"
>
> Answer: "*Yes.*"

68. I put similar questions to Dr. M. I said:

> Question: "*If I were to refuse the orders that are sought - in other words to say No to questions 2 and 3 that you see there, that I would refuse the relief which is sought so you would not be authorised or permitted in the event of a respiratory deterioration to withhold an increase in ventilator support and likewise, No. 3. Does that create any ethical difficulties*?"
>
> Answer: "*I would do it and I would be unhappy doing it, but I would do it. Is that a reasonable answer*?"

> Question: "*That's your answer and you would be unhappy*." (Interjection).
>
> Answer: "*Oh very*."
>
> Question: "*But you would do it because you would not have consent*?"
>
> Answer: "*I would not only be unhappy. I would be upset. And I can entirely understand how his parents would vehemently disagree with me, but I would find it very upsetting to have to do that*."
>
> Question: "*I'm not going to put words in your mouth - would you be doing it against your better judgment*?"
>
> Answer: "*Oh yes*."
>
> Question: "*But you believe you would do it*?"
>
> Answer: "*Oh yes I would. It's the rule of law. I mean, it's the way we work. It's the system, so I have respect for that*."

69. I asked a similar question to Dr. M2 who of course is not the treating physician. This is the exchange which took place.

> Question: "*Would it be fair to summarise your position that if the court were to withhold the order sought, you would be acting against your better judgment in providing the therapies that are identified*?"
>
> Answer: "*It would certainly be against my better judgment*."

70. I now turn to the medical evidence which was adduced specific to each of the two reliefs.

Increased ventilation (Para. 2 of the motion)

71. The court is asked to authorise and permit "… *the persons responsible for the medical care and treatment of the ward for and on behalf of the Health Service Executive, in the event of respiratory deterioration and in the best interests of the ward, to withhold an increase in existing ventilator support*".

72. It is first of all necessary to understand the form of ventilator support that is being provided at present. J.M. has a tracheostomy tube in place. Through that tracheostomy he is being given what is called night time CPAP.

This is continuous positive airway pressure, a form of ventilator support which is administered to reduce the frequency of recurrent respiratory tract infections. This is being administered as a prophylactic measure and it seems to have worked well since he has had no respiratory infections for over a year.

73. This treatment is given only at night and he is on 8cm of water continuous positive pressure. As Dr. N. said they are giving him "*additional pressure so when he inspires he gets a helping hand with that breath*".

74. Increased ventilation support would involve what is called BiPAP which is mechanical ventilation on a continuous 24 hour basis. Dr. N. said:

> *"Once you attach BiPAP now he is attached continuously to the machine. He can no longer be sat out of bed, as he is at the moment, so he becomes continuously ventilated 24 hours a day as opposed to when you look at what happens when he gets his night-time CPAP."*

In addition, BiPAP is administered at a pressure that is higher than CPAP and according to Dr. N.'s evidence it is physiologically different. She said:

> *"It doesn't look much different and actually if you were visiting J.M. as a family member you might think he is just connected to the machine for a bit longer. Physiologically the change that has taken place is quite different."*

In her evidence she made it clear that if J.M. were again to develop pneumonia he would be given IV antibiotics and IV fluids. The problem arises when one comes to consider increasing ventilation to BiPAP. In this regard the evidence of Dr. M., Dr. N. (both treating physicians) and Dr. M2 and Professor B. is instructive.

75. Dr. M. said:-

> *"In relation to increasing the ventilation, he has got a tracheostomy and for him to require an increase in ventilation would mean that we would have failed to control infection with antibiotics, would have failed to control infection with suction, which would be very easy to do in J.M. because of the tracheostomy. It does and has prolonged his life. It would mean that we now have to aggressively ventilate him. He would be likely in those instances where he would get an infection bad enough to require an increase in his level that he would require additional support for his blood pressure plus or minus dialysis because when they get bad infections they get*

multiple organ failure. He has previously survived one episode of multiple organ failure, whether or not we could do some of that I don't know because we had great difficulty in the past because of how sick he was. So it's not the same as intubating somebody who is sitting here who cannot cough. We will be able to cough for him. We will be able to get the secretions out, we will be able to give him his antibiotics and we'll give him fluids, all of which has worked repeatedly over recent times and no one is suggesting that we're not going to do what is, what I would consider, a standard medical therapy, but to aggressively ventilate him again and to change from what is - just at the end of the respiratory cycle to blowing air into him. That is an extremely, in my view, it is just too - it's an escalation that I don't believe is appropriate, that is my view."

The President:-"*Could I just ask you what is aggressive ventilation, what is involved in aggressive ventilation*?"

Answer: "*In J.M.'s instance he has a machine that is attached to him at the moment. It is designed to be used with a mask, not necessarily with a tracheostomy, but we often use it with a tracheostomy. It is designed generally to apply just CiPAP but can be used to apply more positive pressure. What we do with that machine then is, instead of just - you attach a bellows to the lungs and you inflate them with the bellows and how hard you inflate is the pressure that we use*."

Question: "*So it is an increase in the level that you are at*?"

Answer: "*It's an increase*."

Dr. N. described the increase to BiPAP as "invasive ventilation" which would be administered on a continuous 24-hour period. There is no doubt but that 24-hour BiPAP is more invasive than the treatment being administered at present. Being on a ventilator is not comfortable *per* Dr. M.

76. The evidence is clear that neither of the treating doctors N. or M. consider it appropriate or in J.M.'s best interests that there should be an increase in ventilation support. Their view is shared by Dr. M2.

77. The evidence of Professor B., the parent's nominee, and the only consultant respiratory physician who gave evidence and who, of course, is not involved in the treatment of J.M. is very pertinent on this issue.

78. He said in his report on this topic as follows:-

"Firstly, it is important to emphasise that respiratory deterioration is unfortunately inevitable. While J.M. has currently survived multiple episodes of pneumonia and systemic sepsis, there is now evidence of three drug resistant organisms, namely staphylococcus, enterococcus and pseudomonas. Given his atelectasis and lung collapse, retained secretions, inability to clear his own secretion and consequent critical impairment in his pulmonary defence mechanisms, it is only a matter of time before further respiratory infections occur and if this is caused by resistant organisms (which again is unfortunately inevitable), such infection is likely to prove fatal.

An increase in the existing ventilatory support in the event of respiratory deterioration would require transfer to I.C.U. and various forms of mechanical life support. This is a hazardous undertaking, even in the best of hands and even with previously healthy patients. Many significant neurological, cardiac, respiratory infections and other complications are unfortunately well documented and in some cases inevitable sequelae even under optimal conditions. Furthermore, while the normal lungs inspire by creating a negative pressure in the lungs, mechanical ventilation uses positive pressure to inflate the lungs. This is an unnatural (albeit effective) method of ventilatory support. However, pressure related damage (so called barotraumas) is a significant risk and J.M. has already suffered a pneumothorax ("air leakage from a punctured" lung), and is at increased risk to damage this and similar barotrauma as a consequence of his chronic lung disease and smoking related lung damage.

Clearly these complications carry a very high morbidity and a significant mortality risk and so (to answer your question) would obviously not be transient.

I believe J.M.'s condition will undergo further deterioration were his respiratory care escalated to full mechanical ventilation because of the added risks of mechanical ventilation and because such intervention would almost certainly require an escalated level of sedation with potentially severe adverse neurological effects on J.M.'s already significantly compromised neurological status."

79. This evidence would suggest that an increase in ventilation pressure is unlikely to be in J.M.'s best interests.

CPR and related measures (Para. 3 of the motion)

80. There is no dispute whatsoever between any of the medical practitioners who gave evidence as to the inappropriateness of this form of treatment because it is not in the best interests of the ward. Indeed, such was the strength and unanimity of the evidence that Mr. Reidy S.C. counsel for the parents, at the conclusion of the evidence on the fourth day of the hearing, told me that he did not see himself arguing against this relief under any circumstances. He made it clear that he was speaking as counsel in the case and not for the family when he made that comment. He told me that he could not see how he could, as counsel in the case, make an argument that would have any merit against the order sought. As I pointed out that was a perfectly proper position for counsel to adopt. It does not, of course, relieve me from the obligation of having to decide the matter but it does assist me. It also means that insofar as this part of the judgment is concerned it is not necessary for me to quote verbatim from the evidence given by the respective doctors; a short summary of their testimony will be sufficient.

81. The evidence makes it clear that the need for the treatments described in para. No. 3 are likely to arise secondary to sepsis. Dr. M.'s evidence is to the effect that CPR in that setting is very difficult and has a poor outcome. She is supported in that by Dr. M2. In any event CPR is unlikely to be successful. That is the view not merely of Dr. M. but also of Professor B.

82. If CPR were administered there is a risk of J.M. having ribs broken. That risk is increased because of his shape and the fact that he has been in bed for such a long time. CPR would also carry a significant risk of pneumothorax. There would also be pain, discomfort and possible distress.

83. These treatments have a poor outcome. Even if successful they are likely to lead to further neurological deficit thus further reducing J.M.'s existing quality of life.

The legal position

84. The leading case in this jurisdiction concerning medical treatment in respect of a person experiencing a disorder of consciousness is *In Re A Ward of Court (No. 2)* [1996] 2 I.R. 79. That case was decided before the condition known as MCS had been diagnosed. The ward in that case was described as being in a "near persistent vegetative state". It seems highly likely that she was in a MCS. The case is fundamentally different to this one in that what was sought there was permission to withdraw life support which consisted of artificial nutrition and hydration as well as medication. Nothing akin to that is sought in this case. All the evidence is that J.M. will continue to be treated as he has been and indeed, if a deterioration such as infection occurs, he will be given all appropriate antibacterial medication, fluid

support, etc. What I am asked to do is to provide that, in the event of deterioration occurring, there will be no obligation to provide the treatments described as paras. 2 and 3 of the notice of motion. It is the equivalent of asking the court to give what is commonly called a "do not attempt resuscitation" (DNAR) or "do not attempt cardio-pulmonary resuscitation" (DNACPR) direction.

Jurisdiction

85. As J.M. is a ward of court the jurisdiction being exercised on this application is one formerly exercised by the Lord Chancellor of Ireland. That jurisdiction is now vested by s.9 of the Courts (Supplemental Provisions) Act 1961 in the President of the High Court. Accordingly:-

> "*The Court is vested with jurisdiction over all matters relating to the person and estate of the ward and in the exercise of such jurisdiction is subject only to the provisions of the Constitution: there is no statute which in the slightest degree lessens the court's duty or frees it from the responsibility of exercising that parental care*". (*per* Hamilton C.J. in *In Re A Ward of Court (No. 2)* [1996] 2 I.R. 79 at p.106.

Medical treatment

86. "*Medical treatment may not be given to an adult person of full capacity without his or her consent. There are a few rare exceptions to this, e.g., in regard to contagious diseases or in a medical emergency where the patient is unable to communicate. This right arises out of civil, criminal and constitutional law*." (*per* Denham J. in *In Re A Ward of Court* [1996] 2 I.R. 79 at p.156).

It follows that every competent adult has a right to withhold consent to medical treatment. As was said by Hamilton C.J. at p.126:-

> *"I am satisfied that if she were mentally competent that she would have, in the circumstances of her condition, the right to forego the treatment or to have the treatment discontinued and the exercise of that right would be lawful and in pursuance of her constitutional rights".*

87. The right to refuse medical treatment extends to treatment which is necessary in order to protect or sustain that person's life. That proposition was dealt with by a number of the judges in *In Re A Ward of Court* as follows:-

> *"Where a person who is compos mentis has a condition which, in the absence of medical intervention, will lead to death, such person has a right in law to refuse such intervention"* (*per* Blayney J. at p.142).
>
> *"A competent adult if terminally ill has the right to forego or discontinue life saving treatment*" (*per* Hamilton C.J. at p.125);
>
> "*There is an absolute right in a competent person to refuse medical treatment even if it leads to death"* (*per* O'Flaherty J. at p.129).

Effect of wardship

88. "*The loss by an individual of his or her mental capacity does not result in any diminution of his or her personal rights recognised by the Constitution, including the right to life, the right to bodily integrity, the right to privacy, including self determination, and the right to refuse medical care or treatment"*. (*per* Hamilton C.J. at p.126).

That judge went on to say:-

> *"The ward is entitled to have all these rights respected, defended, vindicated and protected from unjust attack and they are in no way lessened or diminished by reason of her incapacity."*

That latter statement finds resonance in the views expressed by Ward L.J. in *In Re A. (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147 at p.187 where he said:-

> *"I conclude that it is impermissible to deny that every life has an equal inherent value. Life is worthwhile in itself whatever the diminution in one's capacity to enjoy it and however gravely impaired some of one's vital functions of speech, deliberation and choice may be."*

Preservation of life

89. "*The nature of the right to life and its importance imposes a strong presumption in favour of taking all steps capable of preserving it, save in exceptional circumstances*." (*per* Hamilton C.J. at p.123).

There exists a "*constitutional presumption that the ward's life be protected*" (*per* Denham J. at p.167). These observations are made in the context of rights derived from the Constitution. But the position is no different at

common law as is clear from the views expressed by Baker J. in *In Re M. (Adult patient) (Court of Protection)* [2012] 1 WLR at p.167 where he said:-

> *"The first principle is the right to life. As Lord Goff observed nearly 20 years ago in the Bland case [1993] AC 789, 863:-*
>
> > *'The fundamental principle is the principle of the sanctity of human life'."*

Munby J. in *R. (Burke) v. General Medical Council* [2005] QB 424 spoke of the "*very strong presumption in favour of taking all steps which will prolong life … the principle of the right to life is simply stated but of the most profound importance. It needs no further elucidation. It carries very great weight in any balancing exercise*".

Protection of the rights of a ward of court

90. It is to this court that a ward of court must look in order to respect and protect from unjust attack the right to life of such a person. There is a very strong presumption in favour of taking all steps which will prolong life. But in exercising its jurisdiction the court is not precluded in principle from finding that in the circumstances of a particular case it is in the ward's best interests that the court should refuse to give consent to a particular course of medical treatment, even treatment which might become necessary or desirable in order to prolong or to attempt to prolong the ward's life. There is no absolute duty imposed on the court to consent to medical treatment on behalf of a ward of court in order to attempt to prolong life at all costs and without regard to any other consideration or circumstance of the ward's best interests. Neither is there any absolute duty on a doctor to provide, or on a patient to consent to, medical treatment in order to attempt to prolong life at all costs and without regard to other matters concerning the patient's best interests. As was stated by Hamilton C.J. at p.124:

> *"The right to life necessarily implies the right to have nature take its course and to die a natural death and, unless the individual concerned so wishes, not to have life artificially maintained by the provision of nourishment by abnormal artificial means, which have no curative effect and which is intended merely to prolong life.*
>
> *This right, as so defined, does not include the right to have life terminated or death accelerated and is confined to the natural process of dying. No person has the right to terminate or to have terminated his or her life, or to accelerate or have accelerated his or her death."*

It follows that there is nothing in principle which would preclude this court in an appropriate case from refusing consent on behalf of a ward to the commencement of treatments such as are identified at paras. 2 and 3 of the notice of motion or to the making of a DNAR direction.

91. If there is nothing in principle to prevent such an order being made what are the criteria that have to be met and what are the matters that should be taken into account on such an application?

The test

92. The test to be applied was identified by Hamilton C.J. in *In Re A Ward of Court (No. 2)* [1996] 2 I.R. 79 at pp.106 and 127 where he said:-

> *"In the exercise of this jurisdiction the court's prime and paramount consideration must be the best interests of the ward. The views of the committee and the family of the ward, although they should be heeded and careful consideration given thereto, cannot and should not prevail over the court's view of the wards best interest."*

Later at p.127 he said:-

> *"In addition, in this jurisdiction the court must have regard to the constitutional rights of the ward and defend and vindicate these rights."*

93. In a case involving a prospective refusal of consent to commence a course of life-saving or life-sustaining treatment the best interests test does not equate to a question of whether it would be in the best interests of a patient that he should or should not die. That would not be a permissible approach. This matter has received statutory recognition in the United Kingdom where under section 4(5) of the Mental Capacity Act 2005 it is provided:-

> *"Where the determination relates to life sustaining treatment he (the decision maker under the Act) must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death."*

That, in my view, accurately summarises the position here having regard to what is said by Hamilton C.J. at p.115 when quoting from the speech of Lord Goff in *Airdale NHS Trust v. Bland* [1993] AC 789. That judge said:-

> *"The question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best*

> *interests of the patient that his life should be prolonged by the continuance of this form of medical treatment or care."*

More recently the Supreme Court in the United Kingdom in *Aintree University Hospital's NHS Foundation Trust v. James* [2013] UK SC 67 stated through Baroness Hale that:-

> *"The question is not whether it is in the best interests of the patient that he should die. The question is whether it is in the best interests of the patient that his life should be prolonged by the continuation of this form of treatment …*
>
> *Hence, the focus is on whether it is in the patient's best interests to give the treatment, rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course that they have acted reasonably and without negligence) the clinical team will not be in breach of any duty towards the patient if they withhold or withdraw it."*

Standard of proof

94. There was a divergence of opinion amongst judges on this topic in the *In Re a Ward of Court* case. In the High Court, Lynch J. held at p.92 that:-

> *"The proper standard of proof … is evidence which should be clear and convincing having regard to the gravity of the matter for decision."*

Hamilton C.J. found no fault with that approach but Denham J. in her judgment said that the onus was on the applicants seeking to end the treatment "*to prove their case on the balance of probabilities*". She did, however, note that "*the court should not draw its conclusions lightly or without due regard to all the relevant circumstances, including the consequences for the ward, the family and the carers involved*".

95. Blayney J. took a different view. He said:-

> *"The learned trial judge clearly treated the case as being a lis inter partes. He referred to the onus of proof being on the committee and he held that the standard of proof was that the evidence should be clear and convincing. It seems to me to be doubtful,*

> *however, if this approach was correct. In a lis inter partes, the proceedings are adversarial and one consequence of this is that the court is confined to deciding the case on the material placed before it by the parties. It cannot of its own motion seek additional information or require any particular witnesses to be called. But such is not the position of the High Court when exercising the former jurisdiction of the Lord Chancellor …*
>
> *If in the present case the learned trial judge had wanted to have a further examination made of the ward, he would have been entitled to direct one. He could not have done so in a lis inter partes. In the circumstances it seems to me that there was no need for the learned trial judge to deal with the onus of proof or the standard of proof but it must be added that the fact that he did so does not in any way affect the decision at which he arrived."*

96. I believe the views of Blayney J. to be correct. This is not a *lis inter partes*. The parents were joined as notice parties. They indicated a desire to obtain independent evidence from their own nominated experts and that desire was given effect to by order of the court. Whilst, therefore, I believe Blayney J. to be correct in his analysis of the jurisdiction being exercised, nonetheless the decision will fall to be made only upon evidence which is clear and convincing.

97. I now turn to a consideration of the factors to be taken into account in assessing a ward's best interests.

Relevant factors

98. Denham J. in the course of her judgment in *In Re a Ward of Court (No. 2)* [1996] 2 I.R. 79, whilst stating that the totality of a ward's situation has to be considered listed fourteen matters in an inclusive list at p.167. They are:-

> *1) The ward's current condition.*
>
> *2) The current medical treatment and care of the ward.*
>
> *3) The degree of bodily invasion of the ward the medical treatment requires.*
>
> *4) The legal and constitutional process to be carried through in order that medical treatment be given and received.*
>
> *5) The ward's life history, including whether there has been adequate time to achieve an accurate diagnosis.*

6) The prognosis on medical treatment.

7) Any previous views that were expressed by the ward that are relevant, and proved as a matter of fact on the balance of probabilities.

8) The family's view.

9) The medical opinions.

10) The view of any relevant carer.

11) The ward's constitutional right to:- (a) life, (b) privacy, (c) bodily integrity, (d) autonomy, (e) dignity in life, (f) dignity in death.

12) The constitutional requirement that the ward's life be (a) respected, (b) vindicated and (c) protected.

13) The constitutional requirement that life be protected for the common good. The case commences with the constitutional presumption that the ward's life be protected.

14) The burden of proof is on the applicants to establish their application on the balance of probabilities, taking into consideration that this court will not draw its conclusions lightly or without due regard to all the relevant circumstances."

99. More recently Kearns P. in *Re S.R. (A Ward of Court)* [2012] 1I.R.305 set out a shorter non-exhaustive list of considerations and concluded as follows:-

"In determining whether life-saving treatment should be withheld, the paramount and principal consideration must be the best interests of the child. This gives rise to a balancing exercise in which account should be taken of all circumstances, including but not limited to: the pain, suffering that the child could expect if he survives; the longevity and quality of life that the child could expect if he survives; the inherent pain and suffering involved in the proposed treatment and the views of the child's parents and doctors."

100. I am also of opinion that it is open to the court in taking all circumstances into account to have regard to clinical or ethical guidelines issued by, for example, the Medical Council or the Royal Colleges.

101. I have already gleaned a good deal of assistance from the working paper from the Royal College of Physicians and I note that it states that decisions about care of patients who lack capacity:-

> *"will need to take account of:-*
>
> • *The likelihood that treatment will be effective or futile.*
>
> • *The benefits, burdens and risk of treatment - the best and worst outcomes.*
>
> • *The patient's likely wishes, based on what is known of their values and beliefs."*

102. In this jurisdiction the guide to professional conduct and ethics for registered medical practitioners which is produced by the Medical Council pursuant to s.7(2) of the Medical Practitioners Act 2007 says:-

> *"46.3 Usually, you will give treatment that is intended to prolong a patient's life. However, there is no obligation to start or continue treatment, including resuscitation,…if you judge that the treatment:*
>
> • *Is unlikely to work; or*
>
> • *Might cause the patient more harm than benefit; or*
>
> • *Is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring.*
>
> *46.4 You should carefully consider when to start and when to stop attempts to prolong life. You should make sure that patients receive appropriate pain management and relief from distress, whether or not you are continuing active treatment."*

103. There is no evidence of any previous views expressed by J.M. which are of relevance. That is hardly surprising given his young age. In such circumstances it seems, to me following the view expressed by Kearns P. in *Re S.R. (A Ward of Court)* [2012] 1I.R.305 at p.323 that,

> *"The proper test in such a case is to ask what the ward would choose if he were in a position to make a sound judgment. It follows that the decision maker should not impose his own views on whether the quality of life which the child would enjoy would be intolerable, but should determine the best interests of the child subjectively."*

That type of subjective approach was approved of in the United Kingdom Supreme Court in the *Aintree* case where Baroness Hale disagreed with the views of Ward and Arden L.JJ. in the Court of Appeal insofar as they "*were suggesting that the test of the patient's wishes and feelings was an objective one*".

Findings on J.M.'s medical condition

104.

> (1) J.M. is in a MCS. That is as a result of a severe, non-traumatic, multifactorial, irreversible brain injury. That brain injury is both severe and irreversible.
>
> (2) J.M. is unable to speak or to communicate his wishes. He is tube fed and dependent for all activities of daily living.
>
> (3) He does have an awareness to some extent at least, of his surroundings. He responds to stimuli by times. His level of awareness fluctuates and is compromised by the impairment of his physical functions. He suffers greatly from fatigue. As a matter of probability he can suffer pain.
>
> (4) There will be no improvement in his neurological position, his ability to function or his level of awareness. The brain volume loss demonstrated by MRI scanning is an indicator of poor prognosis.
>
> (5) He breathes through a tracheostomy. He has a history of recurrent respiratory tract infections and he is at substantial risk of them recurring. Patients with altered states of consciousness with a long term tracheostomy in place eventually succumb to respiratory sepsis.

The plan of the hospital authorities is to keep all of his current supports in place and in the event of infection occurring to treat such infections with antimicrobial treatment and fluids.

Relief No. 3 - Conclusions

105. The evidence on this topic is overwhelmingly to the effect that it would not be in the best interests of J.M. that such treatments should be given. They would involve chest compressions, invasive lines, very significant discomfort and pain. It would not be appropriate that they should be administered unless there were clinical indications that they would produce a clear medical benefit. The evidence strongly suggests that they would not. They would certainly not improve his underlying condition or remove or lessen any burdens experienced by him. Indeed they might well add new

burdens as CPR might, for example, bring about fractured ribs or indeed further brain injury associated with the cardiac output around the time that CPR would be administered. I am therefore satisfied that insofar as this relief is sought the evidence is to the effect that it would not be in the ward's best interests that this treatment should be administered and accordingly I will grant this relief.

106. I am fortified in this view by the fact that counsel on behalf of the notice parties made it clear that he could not, as a responsible member of the bar, argue against the order being sought in respect of these procedures. I believe he was perfectly right so to do.

107. Taking all of the matters which I must take into account, J.M.'s best interests are addressed by granting this relief.

Relief No. 2 - Conclusions

108. In contrast to the approach taken by counsel on behalf of the notice parties in respect of relief No. 3 he urges me to refuse relief No. 2.

109. The argument in favour of this proposition is made by reference to various aspects of the evidence given in particular by Dr. M. and Dr. M2.

110. As I have already pointed out there is virtually no dispute between the medical experts as to the diagnosis, prognosis or appropriateness of the orders sought being granted. The notice parties have chosen some aspects of the testimony to argue that the best interests of J.M. would be addressed by refusing this relief.

111. J.M. receives CiPAP every night. That positive pressure is administered through the tracheostomy. On the past occasions where clinical deteriorations have occurred that has been increased to BiPAP on a 24 hour basis.

112. Because BiPAP is also administered through the tracheostomy it does not involve any further invasive procedure. As Dr. M. said you "*just attach it on and off*". But the mere fact that the treatment can be given without any further invasive procedure is just one element to be considered.

113. Dr. M. was asked about its effects during the past crises as follows:-

> *"Q. I suppose it may be a difficult question to answer but if I go back on it - suppose this order was in place on either of those occasions would he have pulled through?*

A. That's actually, I'm sorry, impossible to answer. It is impossible to answer.

Q. Put in a different way, would his life be at greater risk?

A. If you're talking about quantity of life, yes. Yes. If you mean, would he have been slightly at increased chances of death?

Q. Yes."

Dr. M2 was asked, in effect the same question, but he felt he could only speculate but did say "*my best guess is that the respiratory support change here is minimal and that the response to therapy is probably through appropriate selected antibiotic therapies*".

114. The risks involved in escalating the ventilation were also discussed with Dr. M2. He confirmed that whilst there was always a risk in escalating any therapy BiPAP was one which was relatively safe. He did confirm that there is a risk of lung injury related to the application of the positive pressure involved.

115. He was also asked about the effects of the therapy on the comfort of J.M. as follows:-

"Q. Am I right in just summarising what I understand you to have said about this event is that it more than likely did increase the comfort of the patient but put the patient at some risk of lung damage?

A. I go back to my own interpretation of what works best for the patient is that any therapy that diminishes the effect of the sepsis is bringing the most benefit, so the personal milieu of being septic with a urinary tract or pneumonia in this case, the antibiotics are the main instruments of both therapies and probably of comfort because it is the sepsis itself that makes you most uncomfortable.

Q. Yes, in combination the increase in ventilation and the antibiotics make it more comfortable then?

A. I would think the whole package is important."

116. It seems to me that a fair reading of these answers from Dr. M2 suggests that the principal agent in bringing about treatment of the sepsis was the antibiotic therapy rather than the increase to BiPAP.

117. This evidence has to be contrasted with that which I have already outlined in this judgment from both treating anaesthetists. Dr. M. described it as "*aggressive ventilation*". Dr. N. described it as "*continuous invasive ventilation*". She also described it as a form of "resuscitation". I also have to bear in mind that an escalation in ventilation would require an escalated level of sedation with potentially adverse neurological effects. Neither doctor was at ease at the prospect of having to administer such treatment.

118. I attach considerable weight to the evidence of Professor B. the only respiratory consultant to give evidence. His first report was agreed with by Dr. M. in the course of her testimony. Professor B. had said: - "*since further escalation of respiratory support, i.e., full mechanical ventilation carries significant risks, not only of increased morbidity but also mortality, it is difficult if not impossible to suggest such measures are appropriate in this case*".

119. I also have to bear in mind Dr. M.'s testimony that an increase in ventilation will not return J.M. back to his current condition and that he would probably have an adverse outcome from the point of view of brain function.

120. I have not lost sight of the fact that in his second report Professor B. did say in the event that, despite optimal treatment, J.M.'s condition deteriorated to a point where full mechanical resuscitation was necessary to preserve life, then he believed him to be "entitled" to such resuscitation.

121. The circumstances in which that opinion came to be expressed by Professor B. and his change of view were explained in his evidence. He said:-

> *"Firstly, I think somebody sometime has to make these decisions and I think that there should be, even in the best case scenario, a time limit on when that decision is made. In terms of the guidelines outside of the court, Judge, responsibility for that rests on the lead physician, according to all the internationally accepted guidelines. But the lead clinician - and this is my second point - and I said I had two responses. My second response is that the lead clinician has to, if I may coin a phrase, bend over backwards to include the family in what would then be a mutually agreed ceiling of care and if I may just in that context say in terms of something that was said earlier, my position in both of my reports is that resuscitation is futile in the context in which I have described it, but the difference between my first and second report was my second report was making a plea when I was more aware of a*

communication gap that an effort should be made to bridge the communication gap before definitive orders were put in place without full agreement from the family. But events have overtaken that comment, Judge, by your own comments before you looked for a break."

Thus the comment made in the Professor's second report was made in circumstances where he believed that the communication gap which developed between the notice parties and the medical personnel might still be bridged and consent forthcoming. However, he accepted that that was not a possibility. That was so despite all the efforts made to obtain a consensus view.

122. In the final part of his testimony he answered some questions from me. I have already reproduced this material but it is worth repeating in brief. I asked him:-

Q. "Do I correctly gather from your evidence that it is your professional opinion as a consultant respiratory physician that in the event of J.M. having a respiratory deterioration that it is not in his best interests that he should have any increase in ventilator support?

A. Yes, is the answer to that Judge.

Q. The ultimate decision being with the lead medical physician insofar as that decision is concerned?

A. Yes.

Q. If it were your decision and you were the lead medical physician you would not increase the existing ventilator support in the event of him having a respiratory deterioration?

A. No, I would not, but I would be very disappointed with myself if I couldn't bring a family on board to that, but if I couldn't so be it, I would have to make the decision."

123. As Professor B. testified, J.M.'s condition is likely to undergo further deterioration were escalated ventilation administered. There is the significant risk of barotrauma in an already compromised patient. He will sustain further deterioration if full mechanical ventilation is given. Such would very likely require an increased level of sedation with potentially adverse neurological effects. It will not return J.M. to his present condition and will probably adversely affect brain function.

124. I consider all this evidence in the light of the best interests of J.M. I therefore take account of:

(1) the negative prognosis,

(2) the benefits and burdens of this treatment,

(3) the presumption in favour of life, and

(4) in the absence of J.M.'s wishes being known or ascertainable those of his parents.

125. Having considered all of the medical testimony and the factors which I must take into account I have come to the conclusion that it is not in J.M.'s best interests that he should have an increase in ventilator support in the event of a deterioration in his condition. The risks involved in so doing are substantial. No doctor supports the provision of the therapy. No improvement of his underlying condition will be effected. No lessening of the burden of J.M.'s illness will be brought about. No clear medical benefit will be achieved. The burden of the treatment outweighs such limited benefits as may accrue from it. Notwithstanding his parents wishes I do not believe J.M.'s best interests are served by refusing the application. Accordingly, this relief is granted.

Closing remarks

126. The necessity for this application came about as a result of an inability to obtain the consent of J.M.'s parents in circumstances where his wishes are unknown. In the vast majority of cases, after a process of explanation which may take some time, a consensus is reached between doctors and family members. In the present case that was not possible. That is not a criticism of J.M.'s parents or any of the doctors. The parents take a view which is different to that of all the medical personnel. J.M.'s father told me that he could not have it on his conscience to give such consent and that he would leave it to the court to decide the matter. His mother has a similar approach to the matter.

127. I fully acknowledge the extraordinary lengths that Dr. N., in particular went to in an effort to obtain consensus and it is no criticism of either her or Dr. M. that such was not obtained.

128. I wish to pay tribute and to thank J.M.'s parents for their devotion to their son and for the dignified way in which they have conducted themselves throughout this very difficult litigation. I sympathise with them fully in the position in which they find themselves.

129. I would also like to pay tribute to the two intensivists, Drs. N. and M. who have looked after J.M. over the last number of years. Their medical skill and knowledge was matched by a level of compassion and empathy which does credit to their profession, a fact fully acknowledged by J.M.'s parents.

Health Service Executive -v- J.M. A Ward of Court & ors [2017] IEHC ~ (22 June 2017)