THE HIGH COURT

WARDS OF COURT

[2021] IEHC 655

[WOC Ref: 10625]

IN THE MATTER OF J.J.

RESPONDENT

JUDGMENT of Ms. Justice Irvine, President of the High Court, delivered the 18th day of November, 2020

1. Before I begin, it must be stressed that the application heard by this court in recent months could hardly be more important. It concerns not only the life and wellbeing of a most precious eleven year old boy, who I will refer to as John to protect his identity, but the bond of immense love that binds him to his devoted parents and siblings. I have prepared a separate judgment for John's parents where I refer to John by his true name.

2. A little over four months ago, John was involved in a desperately tragic accident that has left him with severe neurological injuries. However, because the accident itself is not of importance to the decision which I have to make, I do not intend to refer to it in any detail lest by doing so I might reveal John's identity. Regrettably, a disagreement has arisen between John's treating clinicians and his parents regarding what his medical treatment should be in these circumstances. And, it is this disagreement which has brought the parties before the court.

John's Injuries

3. Although I will refer in much greater detail to John's present condition and prognosis later in this judgment, I will set out briefly John's injuries to establish the background to the application. After the accident, John was initially taken by ambulance to a regional hospital where he was found to be unresponsive with a Glasgow Coma Scale of 3/15. Later that day he was transferred to hospital A ("the hospital") where he remains under the care Dr F., consultant

paediatrician and his team. Dr F. is the clinical director of the department of intensive care at the hospital.

4. Imaging carried out following the accident revealed that John had sustained the following injuries:-

(i) A right subdural haematoma with significant brain swelling;

(ii) a fractured left clavicle;

(iii) multiple rib fractures (1^{st} – 5^{th} ribs);

(iv) a fractured right humerus;

(v) pulmonary contusions and pulmonary haemorrhage;

(vi) a Grade 1 splenic laceration;

(vii) fractured pubic rami, and

(viii) maxillary fractures.

5. Because of his brain injury, the neurosurgical team concluded John would not benefit from surgical intervention. However, neuroprotective measures were continued in an attempt to reduce brain swelling. An MRI scan carried out on the brain showed devastating findings. In the days subsequent to his admission to the hospital, John sustained a further bleed into the brain. A subsequent MRI carried out on 8^{th} September, 2020, showed no improvement.

6. Efforts made to extubate John on 7^{th} July, 2020 proved unsuccessful with the result that he was re-intubated within fifteen minutes of the removal of his breathing tube. This was necessitated because of respiratory distress compounded by a condition called dystonia. I will return later to discuss, in much greater detail, the evidence heard by the court as to the effect that this condition has had on John's life to date and how it is likely to affect him into the future. Suffice for the moment to say that dystonia is a movement disorder in which, when it is not fully controlled by medication, causes John's muscles to contract uncontrollably causing jerking and twisting movements. According to John's clinicians his dystonia is currently

"hiding" since brought under control after a period of approximately eight weeks during which he had cruelly painful abnormal jerking movements of all four limbs. As will be discussed below, John's clinicians are very concerned that his dystonia will become deregulated in the future in circumstances which will be expanded upon later in this judgment and that whilst uncontrolled, he will experience great pain.

7. John remained intubated until 29th July, 2020 when he was successfully extubated. And, whilst this must have given great hope to his parents, John has remained in a state of disordered consciousness. He is fed by a nasogastric tube and he has a long-term catheter in situ to facilitate delivery of medications. At times his lungs need to be suctioned to remove secretions. He also has a urinary catheter and is doubly incontinent. John will never be able to walk or move any of his limbs purposefully. It may be possible in the future to hoist John into a seat or even a wheelchair subject to his being strapped in at the waist, chest and possibly the head. A recent examination shows that he cannot see. He will never be able to talk. According to the clinicians in whose care he has been for well over three months, John does not respond to voice, follow commands or acknowledge his surroundings, albeit that both of his parents believe that he recognises their voices and that his eyes do latch on to them. Neither does he outwardly show signs of experiencing pleasure. John is presently in a semi vegetative state and whilst it is possible that he might move into what is described by his doctors as a minimally conscious state, any such improvement would, according to John's clinicians, afford him no improvement in terms of his quality of life or ability to communicate.

8. The court was told that John, whose body is becoming deconditioned due to inactivity is at real risk of developing pneumonia as the winter weather takes hold. Amongst many other risks which could cause him to suffer a respiratory crisis are viral or bacterial pneumonia and Covid-19. And, in the event of a substantial decline in John's condition, it will only be possible to keep him alive by admitting him to the intensive care unit (ICU) where he will be subjected

to aggressive interventions which, if successful, will cause him further injury and pain, will cause his dystonia to re-emerge and expose him to significant pain and distress until such time as it may be brought under control. This might take days, weeks or months added to which his health, following his initial recovery, will be on a weaker trajectory than that which it had been on prior to the commencement of invasive measures.

The Relief Sought

9. In light of his present condition, John's clinicians believe that it is not in his best interests to be subjected to invasive measures in an ICU and that his condition should now be managed within the hospital on a children's ward or possibly in a hospice setting. They consider that John should receive all medication necessary to control his dystonia and to alleviate his suffering as much as possible. His clinicians also believe that if his condition deteriorates due to sepsis or respiratory compromise, he should have physiotherapy and antibiotics if deemed appropriate and, importantly, that if his dystonia escalates, he should receive increased pain-killing medication, even if that medication might cause respiratory depression. The relief claimed by the hospital is set out in detail at para. 4 of the Notice of Motion dated 28th August, 2020:-

> "4. An order permitting the Clinical Director of Children's Health Ireland and the medical and nursing staff of [the hospital] to carry out such medical and nursing and ancillary treatment of the minor as they consider in the exercise of their clinical judgment to be appropriate and in the best health and welfare interests of the minor, including but not limited to:
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> (i) permitting the administration of such medication, sedation or anaesthesia to the minor by subcutaneous, buccal or enteral routes for the primary goal of treating severe breakthrough or terminal neurological symptoms even though the doses

required to alleviate the minor's suffering may have a secondary or terminating effect on the minor's respiratory function;

(ii) permitting respiratory suctioning only when it is apparent to the treating nurses or clinicians that secretions are causing distress to the minor;

(iii) permitting the insertion and reinsertion of nasogastric (NG) and/or peripherally inserted central catheter (PICC) and/or via gastrostomy (PEG) insertion for the delivery of feed or medications targeted at making the minor comfortable and/or alleviating distress to the minor;

(iv) permitting the insertion and reinsertion of urinary catheter and ensuring urinary output;

(v) permitting the administration of such medication to alleviate the minor's constipation;

(vi) permitting the taking of swabs and the extraction of blood for testing;

(vii) permitting delivery of oxygen via nasal prongs, cannula or mask targeted at making the minor more comfortable and/or alleviating distress to the minor;

(viii) permitting the taking of necessary x-rays, scans, ultrasound, CT, MRI or other radiological imaging thought necessary and appropriate in the minor's best medical and welfare interests;

(ix) withholding life prolonging treatments or supports that are not considered to be in the best welfare or medical interests of the minor including:

- the administration of high-flow oxygen, continuous positive airway pressure or bi-phasic positive airway pressure supports;
- rescue breaths delivered via bag or mask resuscitation;
- intubation for the purpose of invasive mechanical ventilation;
- mechanical ventilation;

- inotropes for blood pressure instability;
- cardiac compression for insufficient cardiac output or medical or electrical cardio diversion for cardiac arrhythmia;
- invasive access including intraosseous and central venous access devices, or peripheral intravenous access save those permitted at (i) and (iii) above;
- intravenous fluid replacement;
- the readmission of the minor to an intensive care unit."

10. John's clinicians have explained to his parents what they believe is in their son's best interests. They have sought their consent to adopt the palliative regime mentioned in the last preceding paragraph so that, if necessary, they can give John a subcutaneous infusion in order to reduce his pain without concern that, if such intervention was to trigger respiratory distress, they would be forced to respond by deploying aggressive invasive measures such as artificial ventilation and cardiopulmonary resuscitation ("CPR"). And, if John's condition deteriorates to the point that, to save his life, interventions of this type would be required, they believe that it is in John's best interests that these interventions should be withheld. In particular, they want the discretion to withhold, amongst other treatments, endotracheal intubation and the delivery of positive pressure ventilation or oxygen.

11. From the time he was extubated and up until 29th September, 2020, John's dystonia was not under control. And, it is undoubtedly the case that the pain associated with John's dystonia influenced the urgency adopted by the hospital in bringing forward this application. Furthermore, as will later become clear, John's dystonia clearly influenced the manner in which the application was initially heard by this court when it first heard evidence on 15th and 16th September last. The application proceeded on the basis that it was unlikely that John's dystonia would ever be brought under control.

12. John's parents, however, do not take the same view as John's clinicians and oppose the application. John's father remains unconvinced that John experiences pain during a dystonic episode. And, he believes that John would want to live out his life the best way he could even if that involved experiencing significant pain. John's mother, on the other hand, accepts that John did have pain during dystonic episodes but she told the court how she could soothe that pain and how she believes the dystonia might be kept under control. She was certain in her evidence that John would want to receive all treatment that would prolong his life regardless of its side effects or consequences.

The Proceedings

13. In circumstances where John's clinicians were not in a position to obtain the consent of his parents to the managing of his dystonia in the manner proposed and to the withholding of the life prolonging treatments identified in the Notice of Motion, the hospital issued an originating summons under O. 65 of the Rules of the Superior Courts to take John into wardship. In addition, by *ex parte* application made to this court on 28th August, 2020, I was asked by the hospital to make a number of orders. Only two of these need to be mentioned. The first was that I would appoint a guardian *ad litem* to represent John's best interests in these proceedings. I acceded to that application and appointed Mr. Niall McGrath, Solicitor of MacCarthy and Associates, to be John's guardian *ad litem*. The second order sought was to give directions concerning a motion which the hospital was anxious to have determined with some urgency. I directed that the proposed motion would be returned before the court for further directions on 2nd September, 2020.

14. On the aforementioned return date, I was pleased to see that John's parents, who separated from each other in 2017, were both in attendance and represented by solicitor and counsel. Present also was Mr. McGrath who indicated to the court that he was in the process

of trying to get his own independent medical opinion, hopefully from a paediatric neurologist, who might advise him as to what he/she considered would be in John's best interests having regard to the application before the court. In circumstances where the guardian *ad litem* was, with the support of John's parents, in the process of obtaining such a report, I indicated that I did not consider it necessary, at that point, to myself seek an independent report concerning John's best interests.

15. At that time the following evidence had been served by the hospital:-

(i) the affidavit of Dr F., consultant paediatrician at the hospital, which exhibited a report dated 14th August, 2020 signed by Dr F. and the five consultant paediatricians charged with John's care;

(ii) the medical social work report of 17th August, 2020 expressing the concerns of John's medical social workers, A. C. and A. M. J.;

(iii) the report of Dr W., consultant paediatric intensivist at hospital B, that report (dated 27th August, 2020), having been obtained by the hospital as an independent second opinion concerning the best interests of John;

(iv) the affidavit of Dr M., consultant in paediatric palliative medicine at the hospital; and,

(v) the affidavit and report of Dr G., consultant paediatric neurologist at the hospital.

16. Immediately following upon the directions hearing, Mr. McGrath visited John in hospital and met with his parents so that he might understand what they considered was in his best interests. Having done so, Mr. McGrath swore what can only be described as a most comprehensive affidavit on 4th September, 2020 detailing his engagement with John's parents.

17. In his affidavit, Mr. McGrath helpfully explained John's mother's belief that his dystonic movements might not be evidence of pain but rather might be voluntary movements evidencing some recovery. He also relayed her belief that John might emerge from his present

condition and commence the process of relearning. Mr. McGrath further reported that John's mother was anxious that not only would a further medical opinion be obtained but that a further brain scan would be undertaken to identify any possible improvement in his condition. In his affidavit, he told the court that John's mother found it hard to accept that John might not wake up at some point in the future and that "to take him away now" would be murder.

18. Mr. McGrath was successful in obtaining a report from Dr L., consultant paediatric neurologist in hospital C. That report is dated 9th September, 2020, and once received, was circulated to all parties. In light of the fact that there was no conflict in the medical evidence and John's parents did not themselves indicate that they would adduce any medical evidence on the hearing of the hospital's motion, I did not consider it appropriate for the court to seek its own independent medical advice as to what would be in John's best interests.

19. The evidence already mentioned was later supplemented with an ophthalmic report prepared by Ms. C., consultant ophthalmologist, dated 16th September, 2020, a copy of the nursing records from 27th June, 2020 to 1st September, 2020 and a copy of the chart noting John's dystonic episodes from 8th to 15th September, 2020 inclusive.

20. Accordingly, with the agreement of the parties, the hospital's application was listed for hearing on 15th September, 2020.

21. On 15th and 16th September, 2020, I heard the evidence adduced by the hospital and John's guardian *ad litem* and evidence given by John's parents. Later, having heard legal submissions from the parties, I indicated that I would deliver judgment on 9th October, 2020.

22. Judgment was not delivered as planned in circumstances where on the morning of 9th October, 2020 the court's attention was drawn to the content of three medical reports prepared the previous day by those who are principally responsible for John's care. These reports highlighted that there had been a significant improvement in John's dystonia since the case had concluded. Given the hospital's reliance upon the fact that it was unlikely that John's dystonia

would ever be brought under control in support of its application, I considered it important that the court would hear further evidence regarding John's dystonia and his likely prognosis in terms of pain in light of his improvement. In particular, I considered it vital that John's parents and his guardian *ad litem* would have an opportunity to further interrogate his clinicians on this issue. I directed that I would hear further evidence on Wednesday, 14th October, 2020. I also heard supplemental submissions on 21st October, 2020.

Miscellaneous Matters

23. Before dealing with the substance of the present application, two matters should be noted. First, on the opening of the application on 15th September, counsel for the hospital, Mr. Dignam, S.C., made clear that included in the treatments that the hospital would continue to deliver to John in the event of the court granting the relief sought would be the administration of antibiotics and the delivery of physiotherapy, if and when required.

24. The second matter that I would wish to record is that prior to the commencement of the first hearing, I indicated to John's parents that in other cases of this type, the presiding judge had visited the patient at the heart of the proceedings and that if they wanted me to adopt this approach, I would be happy to do so. However, I also indicated that I had given the matter some consideration myself and I felt for a number of reasons that such a visit could not really add anything to the proceedings. I indicated that I was concerned about the risk of bringing infection into the hospital having regard to Covid-19. More importantly, having no medical knowledge and in circumstances where I would not be entitled to bring anything that I saw concerning John's condition to bear on my judgment, my instinct was not to attend. And, it would seem that John's parents must have agreed with my own view in circumstances where they indicated that they were not anxious for me to visit John.

The Evidence

25. Because of the enormity of the decision that I must make for all concerned with this application, I believe it is important that I set out relatively extensively the evidence upon which I have relied in reaching my conclusions. Because of the change in John's circumstances which occurred after the court had first heard this application on 15th and 16th September last, I think it best to summarise, by reference to the individual clinicians, the evidence given at that time regarding John's dystonia. I have decided to take this approach because John's dystonia has not gone away. It is in hiding and highly likely to re-emerge and cause John immense distress. The only question is when and in what circumstances this will happen and how long it will take to get it back under control. Having done that, I will then summarise the evidence given by the same clinicians on 14th October 2020.

Dystonia: Evidence Given on 15th and 16th September

26. As briefly mentioned above, dystonia is a condition that causes involuntary and prolonged contraction of muscles, in John's case of all four limbs, which in turn causes pain to the sufferer. It is often caused by trauma to the brain, in particular the basal ganglia, which then sends out abnormal electrical signals to the muscles.

27. Concerning John's dystonia, Dr F. told the court that cumulatively on any given day, John was experiencing dystonic episodes that might last for anywhere between three and five hours. The nursing records, which he stated would give a clearer picture, showed that for the period of 8th to 15th September, 2020 that on the best of these days, John endured dystonic episodes which cumulatively lasted in excess of two hours and on the worst day, in excess of seven hours. Of particular note is the fact that twelve of the episodes that week lasted longer than an hour.

28. Dr F. explained how John's dystonia was triggered by a range of factors particularly those which made him feel uncomfortable. These included noise, urinary retention, defecation, the presence of a wet or dirty nappy, washing, repositioning and the delivery of medical intervention. Other times it occurred without disruption or disturbance.

29. Dr M. explained that for many patients, dystonia may only involve one area of the body but for John it affects all four limbs such that they go stiff and remain tense for long periods of time causing him to distort his body despite very high doses of background medication. The pain from dystonia itself can then cause further dystonia and this may lead to what is referred to as a dystonic crisis. John had already experienced one life-threatening dystonic event.

30. The clinicians responsible for John's care and the two independent experts who gave evidence to the court *i.e.* Dr W., paediatric intensivist, from hospital B and Dr L., consultant neurologist, from hospital C, were all in agreement concerning the severity of John's dystonia and the distress it was causing him. They explained that John's distress could objectively be ascertained. When experiencing a dystonic episode John's heartrate would escalate, he would sweat profusely and his creatinine kinase ("CK") enzyme would rise, the latter being an indication of muscle breakdown. Describing the severity of his dystonia in the eight week period, leading up to the hearing Dr M. stated that she thought John's dystonia was very painful and distressing for him. She told the court that she had looked after children with far less severe dystonia than John's and the continual message from those children who could speak, and indeed from adults in similar circumstances, was to cry "*help me. I'm in pain … Why can't you do more*".

31. Influenced by his experience of dystonia in awake patients who reported how distressing the symptoms are, and having regard to the objective signs already mentioned, Dr F. was satisfied that John was suffering pain and he told how it was difficult for him and for other doctors and nurses to watch John experience such pain. It was the frequency and severity

of his dystonia and the foreseeability of his deterioration that made John's burden different from any other case of this type.

32. Dr W. told the court that in her nine-year period in Great Ormond Street Hospital, she had cared for between 100 and 150 children per year who suffered from neurological dystonia and that, with one exception, John's case was the worst she had ever seen. She was certain that John was bearing a terrible burden as a result of his dystonia and she described how even in response to her strange voice, his heartrate went up and his dystonia became more severe. Dr W. also explained how any illness makes dystonia significantly worse and, giving an example, she explained how even well-controlled dystonia goes "*off the charts*" when the patient has something as benign as a head cold. She also told the court that while driving over to examine John she found herself wondering why the hospital was asking the court to intervene quite so soon after his accident. However, having examined John, she considered the approach of the hospital to be absolutely warranted in light of the severity of his dystonia.

33. Regarding efforts to control John's dystonia, a number of clinicians described the manner in which the dystonic episodes were treated. If a dystonic event did not settle in fifteen minutes, treatment would commence. If it continued for a further fifteen minutes, a second level of medication would be introduced and the same thing would happen after 45 minutes when additional drugs would be introduced. At 60 minutes, John would receive a subcutaneous bolus injection. If he had a dystonic crisis, that could only be managed by inducing sedation and sleep. The difficulty with sedation, according to John's clinicians, is that whilst it reduces pain, it can cause a reduction or an inefficiency in his breathing. This in turn might precipitate a respiratory collapse which would require the very type of interventions that the hospital considers are not in John's best interests. And, the evidence was universal and clear that the interventions that would take place in intensive care would, because of their severity, ultimately make his dystonia more severe and harder to control.

34. Concerning the ability of the clinicians to control John's pain, the hospital pointed to one dystonic episode which had lasted for 2 hours and 55 minutes before it was brought under control. They referred to the fact that John had developed a high tolerance to medication over time and they felt there was no guarantee that they would be in a position to maintain the *status quo*. The clinicians explained how patients tend to become resistant to treatment. Prof. D. was clear in his evidence that intervention in intensive care would certainly deregulate the control of John's dystonia for a period and there could be no guarantee that his current drugs would work again.

35. Dr G. described John as being in a cycle of pain in which dystonia is triggered by a noxious stimulus and then the pain from the dystonia itself causes further dystonia and, consequently, further pain.

36. In light of evidence of this nature concerning John's pain it is perhaps not surprising that when they first gave evidence on this application, John's clinicians told the court that they felt that their primary goal should be to make him as comfortable as they can whilst recognising that such an approach could impact on his respiratory status. They did not believe that they should hold back on pain killing medication and let John remain in dystonic distress because he did not have a voice to explain how intolerable his pain was. They explained why there was justification for increasing his medication in order to reduce his suffering, even if such an approach could lead to respiratory compromise or a terminal event. All accepted that an increase in medication had the potential to suppress John's ability to cough and his ability to remove secretions from his airways and that these events could threaten his life absent ICU interventions. And, John's clinicians were adamant that should any crisis arise which John might not survive without invasive measures that he should not be taken to ICU to receive them.

Supplemental Evidence Regarding John's Dystonia Heard on 14th October, 2020

37. When the court resumed to hear additional evidence on 14th October, 2020, six additional reports were admitted into evidence. Three of these were from John's treating clinicians, namely Drs G. and F. and Prof. D. The others were from Dr L., the consultant neurologist retained by the guardian *ad litem* and the final two prepared by the nursing staff responsible for John's care.

38. In their reports, Dr G., Dr F. and Prof. D. made clear that there had been a significant improvement in the severity of John's dystonia since 29th September last. His symptoms were responding to the combined effects of a number of drugs including Clonazepam, a benzodiazepine. The dosage of this drug had been increased slowly over seven days and it was this change that was considered responsible for bringing John's dystonia under control. Prior to 29th September, 2020, John had required rescue medications often multiple times per day to terminate prolonged episodes of dystonia. However, since 29th September, John's dystonia had not been interfering with his activities of daily living. He could be dressed, toileted and bathed without these activities producing spasms or obvious pain.

39. Notwithstanding this very positive and welcome improvement, which ran counter to their expectations as earlier expressed, John's clinicians were uncertain as to how long his dystonia might remain controlled.

40. Importantly, the clinicians were certain and unanimous concerning two matters. First, that it was inevitable that John's health would become critical to the point that without the delivery of aggressive invasive measures in ICU he would die and that, if this happened, it would not be in John's best interests that invasive measures be used to extend his life. Second, there remained a possibility that John's dystonia would become deregulated and his symptoms so severe that they could only be controlled by medication delivered at a level and in a manner which carried the risk of depressing his respiratory reserves thus potentially placing his life at

risk. Again, the clinicians were unanimous in their opinion that, in such circumstances, it would be in John's best interests that he would receive the painkilling medication required and that if this caused respiratory compromise invasive measures should be withheld.

41. Of particular importance was the evidence given by each of the clinicians that the deployment of invasive measures in an ICU setting would cause John pain that would destabilise his dystonia, and that it could take days, weeks or months to bring it back under control only to have the whole cycle – crisis, followed by invasive measures, followed by pain, followed by deregulated dystonia, followed by poorer health – repeat itself until such time as John might succumb.

42. Besides their providing their expert reports, which were admitted into evidence by agreement, the clinicians also gave oral evidence.

Dr F.

43. Dr F. explained that it was uncertain as to how long the present alleviation of John's dystonic symptoms might last. He explained that patients become intolerant to medications and if this was to happen his symptoms would re-emerge. Inflammation from an infection, the onset of any type of pain or the introduction of antibiotics to treat an infection could also interfere with the control of John's dystonia. As a matter of certainty, invasive measures in ICU would provoke a dystonic crisis but so also could less extreme events. Furthermore, outside of the setting of ICU, medications which carried the risk of respiratory or cardiac suppression might be needed to reduce the pain caused by John's dystonia.

44. In the event of a crisis where John's life could not be sustained without invasive measures such as respiratory or cardiovascular support or resuscitation, Dr F. stated that it was not in his best interests to receive such treatment. Such measures would not only be distressing but they would cause the deregulation of John's dystonia thereby subjecting him to significant

pain. Furthermore, the effect of pursuing that approach would be to take John away from his family him for a purpose that, according to his clinicians, would bring him no personal benefit. Dr F. accepted that the pain caused by John's dystonia was a significant element in the hospital's concerns when the application was first brought to the court, but it was not the only reason for the hospital's concern. Because John had had two months of dystonia meant there was a strong likelihood that it would recur and that this could happen *"this evening, tomorrow or in a month or six months' time*". It was necessary to plan for such contingencies and remove the possibility that urgent decisions regarding life-saving measures would be made in an intensive care setting.

Dr G.

45. Dr G. stated that while it was excellent news that John's dystonia was currently well-controlled, that position was likely to change. She explained how sometimes medications stop working and patients become immune to drugs and that dystonia can be triggered by infection, discomfort, or even a sore tooth. Importantly, Dr G. advised that it is because invasive measures are painful that they trigger dystonia and the problem is that when dystonic pain re-emerges you simply cannot attack it and take it away. Medication has to be increased slowly for fear of causing respiratory collapse.

46. Because of what is shown on John's MRI brain scan, the fact that he had already experienced one dystonic crisis and it had taken so long to bring his symptoms under control, Dr G. was 80% – 90% certain that his dystonia will re-emerge. And, when it does, it might take days, weeks or months to get it back under control. This is because the process involves switching drugs and changing dosages. Regrettably, during all of that time John would experience very significant distress.

47. Dr G. nonetheless agreed that John's long-term response to Clonazepam would only become clear with the passage of time and that if he was to get long periods of remission from his dystonia, it would certainly improve his quality of life and make his daily functioning easier. In response to counsel's suggestion that it was too early to know what John's baseline would be in terms of dystonia and that it was possible that he might get a long period symptom free, Dr G. agreed that it was possible that he might get a lengthy period symptom-free but considered it very unlikely. She gave three reasons to support her opinion. First, she stated that John's prolonged period of poor dystonia control was a bad prognosticator. Second, because his dystonia is triggered by infection, and John has multiple risk factors for developing infection, he was at high risk of early recurrence. Finally, Dr G. relied upon the fact that John's dystonia is triggered by any type of pain, such as that caused by constipation, urinary tract infection, bed sores, pain in a joint etc, all of which were ongoing everyday live risks for John.

48. Dr G. told the court that the fact that John's symptoms from dystonia had been brought under control should not be seen as an improvement in his overall condition. It was simply that his drugs were keeping his symptoms at bay. His general condition remained the same. And, to demonstrate her point she referred to the fact that John still does not interact with his environment. He does not smile or cry in response to something appropriate and could not, for example, enjoy a cartoon.

49. As to whether the application was warranted having regard to the significant change in John's dystonia, Dr G. stated that as far she was concerned the same level of urgency pertained. Her opinion was that the whole situation could change very quickly, over a period of hours or days.

Dr L.

50. Dr L., stated that there had been no overall change in John's condition, save for the suppression of the dystonia. The fact that because his dystonia was suppressed he might in the future be able to be held in a chair in a seated position should not be interpreted as a sign of any clinical improvement. His motor function would remain the same even if the fact that he could sit in a chair might help with this care. Being able to be seated for a period might help John avoid developing pressure points and could assist with his bowel function. As for the possibility of John using a wheelchair, again that was not any indication of improvement. The wheelchair would only be a means whereby others might move him about and Dr L. cautioned about the use of a wheelchair in circumstances where almost any stimulation risked triggering John's dystonia.

51. Dr L. stated that it was not too early to put a plan in place for what should happen if John was to meet with a medical crisis or his dystonia was to go out of control. While his medical situation was less precarious than before all, if any single step in his daily care was neglected or missed, his health was at risk of deteriorating. She stressed that every single aspect of every single minute of his day had to be managed because John could do nothing for himself. He was not able to communicate or even move voluntarily. So, while the abnormal electrical signals are currently being suppressed by Clonazepam, they are likely to re-emerge because the injury and therefore the dystonia are still there. Dr L. told the court that it was dangerous to assume that just because John's dystonia had been brought under control once that this could be done again. And, the fact that it had been brought under control once was not necessarily a positive indicator.

Dr W.

52. Dr W. agreed that the application could not be viewed as being as urgent as it was when it had first come before the court, but she stated that there was no knowing when John might get an intercurrent illness. Due to his deconditioning John was likely to require early ICU intervention. And, experience suggests that once that process commences the incidents which require the use of invasive measures to sustain the patient tend to become more frequent and the crises more aggressive. According to Dr W., ICU type invasive measures would not be without a cost to John. When asked if it would not be better to wait to see what John's baseline might be before bringing an application such as this, she pointed to the concern that if John was to get a dystonic crisis following a snuffle or cold, without court intervention, it would be likely that he would have to be put through the full gamut of ICU interventions.

53. Dr W. agreed that the benefit of having a plan in place was that it would ensure that interventions were not delivered that were contrary to John's best interest. And, if John was her patient she would not think it was in his best interests to receive invasive measures only to be returned first, to a period of significant pain from his dystonia which would become deregulated and second, to a state of health which would be poorer than that which he enjoyed before the crisis which had taken him to ICU. The only downside of the present application was from the family's point of view as they want him to live for as long as his life can be sustained using all available interventions.

54. Dr W. stated that she did not consider the fact that John might at some stage sit in a chair or use a wheelchair, because his dystonia was currently under control, signalled an improvement in his condition. She nonetheless acknowledged the fact that as John was not currently in distress had afforded his clinicians an opportunity to acquiesce to the family's preference to have more time with John.

Prof. D.

55. Prof. D., paediatric intensivist, was of the opinion that the improvement in John's dystonia made the likelihood of an imminent cardio respiratory deterioration or major aspiration less likely than it had been when the application was first before the court. However, the fact that his dystonia was under control did not affect his analysis of how John would come out of an episode if readmitted to ICU. He stated that presently John is as well as he will ever be and that being so the hospital had an opportunity to try to put a plan in place to provide for what should happen if, for example, John was to develop a crisis as a result of picking up Covid-19.

56. Whilst he is no longer part of John's clinical team, Prof. D. explained that when he signed the first medical report in this case, the team anticipated that John would hit a crisis and end up back in ICU as early as September 2020. However, the deconditioning of John's condition which was expected at the time the application was first made will now take more time to evolve given that he can benefit from physiotherapy. Prof. D. also stated that he probably would not have signed that first report if John had been in his present condition at that time. Nonetheless, he explained that it is better to have a plan in place because without it, decisions are often made in the throes of a crisis that are difficult to unwind.

57. Prof. D. stated that even if the order sought by the hospital was to be made, the hospital would not shutdown dialogue with John's family. And, his understanding of the order sought is that it would not oblige the clinicians to withhold invasive measures if they considered they were in John's best interests in any given set of circumstances. If there was profound disagreement the doctors would have to call it as to what they considered was in John's best interests.

58. Prof. D. confirmed that if John was to present to ICU that evening, i.e. the 14th October 2020, it would not be in his best interests for his clinicians to initiate CPR. And, clarity

surrounding whether or not invasive measures had to be deployed was essential if there was to be any prospect of discharging John back to a regional hospital close to his home. Those hospitals have little experience of paediatric critical illness and, in the absence of clarity, decisions might be made that were not in John's best interests. Such hospitals have no paediatric neurosurgery department or paediatric intensive-care. If a crisis arose they would have to initiate a chain of events to have John taken back to a specialist hospital such as that where he is currently receiving treatment.

Dr M.

59. In explaining John's present condition, Dr M. described his dystonia as having been dialled down and his symptom burden as having been reduced since she had first given evidence. However, the control over John's dystonia had not, in her view, changed the benefit-burden analysis that would be required at the point when John might either need invasive measures to keep him alive or require medication to deal with pain caused by a dystonic crisis. She explained that when she used the word "burden" in this context she was referring to the consequences of CPR if invasive measures were required or the pain that John would experience as a result of withholding medication in the event of a dystonic crisis. It was her opinion that the ICU interventions would not bring John sufficient benefit to counter the significant burden that they would impose. And, if required, invasive measures would be no less burdensome than if they had been required a month ago. Neither the burden nor the benefit attached to either decision had changed. Accordingly, the purpose of putting the plan in place had not changed, even if John's symptoms had improved.

60. Dr M. also confirmed that John's treating clinicians had fully discussed this case subsequent to his improvement and they remained strongly of the belief that a personalised

plan for John needed to be put in place because an agreement cannot be reached with his parents. And, there was no dissent concerning the hospital's current approach.

61. Dr M. strongly disagreed that it was too early for the hospital to bring this application. She said that the hospital had had enough time to fully evaluate John's condition and prognosis. John's clinicians know and understand the impact that his brain injury is going to have on him for the remainder of his life. She stated that there was not a specific length of time that a child should have to wait before good decisions were made in respect of any aspect of their life. It was Dr M.'s opinion that John should not be exposed to further ICU interventions. In response to a suggestion that the hospital should wait and see how John's condition might progress over the longer term, which might include another period in ICU, Dr M. stated that it should not be the case that a patient should have to endure a number of ICU admissions before they had a right not to have them. She pointed to the fact that most people in the world die and never go to ICU. They are allowed to die a natural death. And, the frequency with which John might need to go to ICU should not be allowed to determine the appropriateness of withholding the interventions, because it was the awfulness of the interventions that must be the determining factor. Furthermore, the hospital in this case had had a much longer time to try to reach agreement with John's family than in many other cases. And, that lack of success exposed John to a risk of pain and distress that he should never have to bear.

62. As far as Dr M. was concerned the hospital had to be allowed to use enough medication to give John symptom relief in the event of a dystonic crisis, even if a secondary consequence might be that the medication might depress his respiratory reserves. And, the hospital was committed to trying to avoid such secondary consequences. It was important that clinicians did not avoid treating John's distressing symptoms because they were afraid of causing that effect. The primary goal had to be to make the patient comfortable.

63. Dr M. explained that there are circumstances in which it will not be in the best interests of a patient to interfere with what she described as a natural death. Sometimes invasive measures offer the promise of an improved quality-of-life or an ability to live well in the future. But there are other times when invasive measures do no more than prolong and sustain life without wellness and without quality. And this was such a case. Dr M. emphasised that even if the order sought was to be granted the hospital was committed to doing everything possible keep John's condition stable and keep him well and alive for as long as possible. The fact that the clinicians might, for example, want liberty to withhold drilling into John's bone marrow to deliver antibiotics, did not mean that it would not proceed to give those antibiotics by other, less invasive means.

64. Finally, it would be remiss not to report Dr L.'s evidence concerning the devotion of John's parents, particularly his mother, and also his siblings when she stated concerning their care, that "*[John] couldn't be more loved*" and "*he couldn't be more beautifully cared for*".

Condition and Prognosis

65. Whilst there exists no standardised paediatric test by which John can be stated to be in a persistent vegetative state or a minimally conscious state, Dr G. described him as being somewhere in between, but considered that his current presentation was more in keeping with a persistent vegetative state. She said those in a minimally conscious state will have clearly discernible behavioural evidence of awareness of self or environment and she did not consider John to have either. He has no language or words. He does not grunt or deliver a yes/no expression. John does not, she observed, fix or follow with his eyes and this had been confirmed by his recent ophthalmology assessment and the report of Ms. C.

66. According to Dr G., whilst it was too early to say definitively where John would end up in terms of his long-term prognosis, at best he might achieve a minimally conscious state but the likelihood was he would remain in a persistent vegetative state.

67. Relying upon MRI scanning, Dr L. concluded that John has lost so much brain tissue that whilst it was possible his condition could evolve into one which might be described as a minimally conscious state, her opinion was that he would remain in a persistent vegetative state.

68. Dr L. went on to explain to the court the limitations for John in terms of his future life. She told the court that John was not going to walk, and he was not going to talk. She explained that John would not develop any meaningful awareness of his surroundings and that he would be profoundly and severely neurologically disabled for the rest of his life. She said that John will never be able to communicate how he is feeling and that he will never be able to perform any voluntary movements. According to Dr L., John will probably never be able to process any information given to him to enable him to communicate back to his parents or anyone else.

69. Concerning the quality of and meaningfulness of John's future life, Dr L. observed rather poignantly: "*I think what gives anybody's life meaning is their ability to interact with their surroundings and their ability to feel happiness and love. Currently we know that [John] feels pain and we don't know of anything else*".

70. Prof. D. also expressed the view that John would remain in a persistent vegetative state and would never be better than minimally conscious. And, he told the court how his body will start deconditioning over the next while. John's cardiac respiratory reserves will diminish week on week and year on year. Because he is not mobile his musculature and strength will decline, and John will have increased difficulty in clearing his secretions. He will become prone to aspirating his food and this will place him at risk of pneumonia and a need for intervention measures of the type mentioned at para. 4 (ix) of the Notice of Motion.

71. In support of John's mother's earnest plea that the court would refuse the present application so that John could be given more time to improve, counsel put to each clinician that there was some degree of uncertainty about the extent to which John might recover from his injuries. Counsel placed emphasis on what she described as an improvement in John's Glasgow Coma Scale reading and a reported reduction in his CK enzyme. The clinicians' attentions were drawn to the fact that John's mother and father both believe that he turns his eyes towards them when hearing their voice and that he can suddenly become calm when he hears his brother's voice. Emphasis was placed upon the enormous improvement in the control of John's dystonia which had been achieved between 15th September and 14th October, 2020. Counsel also relied upon the fact that there were also plans underway to try to seat him in a chair and splint his limbs. Based upon these signs it was suggested that the level of recovery that John might achieve, if given sufficient time, remained uncertain and that it was simply too early to withhold invasive measures that would extend his life.

72. In response, all of the clinicians who gave evidence acknowledged that John had some sense of awareness, given that he responded to pain. Dr W. gave evidence to the effect that John's heart rate rose in response to her unfamiliar voice on the date she attended to examine him and that his dystonia increased in response to her effort to conduct a physical examination. Dr M. told the court that she had seen John tear up as a response to distress. All were agreed that John had to have some sense of awareness of his surroundings and of discomfort given that his dystonia was triggered by events which caused him discomfort. Nonetheless, they were united in their view that whatever progress John might make, at best he might attain a minimally conscious state which would have no beneficial effect in terms of his potential to enjoy life. His physiological decline was inevitable, according to Prof. D., and all interventions that might occur in ICU would do no more than put John on a worse trajectory than he is already on. According to Dr G., to give John more time within which his consciousness might increase

into a minimally conscious state would be to make him more aware of pain and that pain would then trigger more dystonia; she said: "*the more you are aware of your surroundings the more you can feel pain. The more pain the more impact on the quality of life*".

Nature of the Interventions the Clinicians Seek Permission to Withhold

73. Relevant to my decision as to what I believe John would consider to be in his best interests is an understanding of the nature of the interventions which the hospital would wish to withhold in the event of a crisis. That being so I consider it important to give some small amount of detail as to what some of these, particularly the invasive measures, entail. These are set forth at para. 4 (ix) of the hospital's Notice of Motion.

74. Whilst these interventions are nearly always carried out when the patient is sedated, it is the damage that would be caused by these interventions in the short and long-term that principally motivates the present application. It has been explained that in the event of a crisis it would be usual that the patient would need all of the interventions listed. However, for present purposes I think it sufficient to briefly focus on the overall impact that these invasive measures would have, first on John's condition and prognosis and second on the level of pain that these measures would cause, assuming he would survive a period of crisis in ICU. Before doing that, I will briefly refer to one or two of these invasive measures so that the reader can better understand the severity of the measures which, in practice, would have to be taken to maintain John's life in the event of a crisis, without the consent of John's parents or an order of this court.

75. Cardiopulmonary Resuscitation ("CPR"), one of the interventions which the clinicians want to have discretion to withhold, was described graphically by many witnesses. Dr F. described how the chest is forcefully compressed 60 – 100 times a minute and how he anticipated this would probably fracture several of John's ribs apart from causing him severe

bruising and contusions. Such injuries, according to Dr F., would leave John in a much greater state of pain than he would have been in before the crisis and this pain would trigger his dystonia which, even if it had been stable for some time prior to infection or crisis, would become destabilised and it might or might not be possible to re-stabilise it. Dr G., amongst others, stated that CPR would only cause John even greater suffering than he currently endures and in circumstances where it would deliver no long-term benefit.

76. As for ventilation, Dr L. explained that the process commences with the child being intubated. This involves the introduction of a metal blade into the throat which has the prospect of damaging teeth and lacerating the throat. The tube can be misplaced and lead to a collapse of the lungs. Prof. D. spoke of how being on a ventilator could weaken John's heart and, if he survived the crisis, that he would need frequent physiotherapy and suctioning, interventions which of themselves would increase John's dystonia. In particular, he explained how these invasive therapies would not only cause John great distress and potential harm but they would do nothing to improve his underlying condition. At best they would provide an artificial bridge to a life in which John would have to endure significant pain and, in all likelihood, place him on a poorer health trajectory than that which he had been on prior to the intervention. And, he told of how chronically ill patients are rarely the same at the end of a period on a ventilator.

77. The universal view of the clinicians was that following a period of invasive measures in ICU, John would be left in a much-depleted condition. The present control over his dystonic pain will probably be lost if he gets an infection, as all discomfort exacerbates dystonia, allied to the fact that the necessary change in his medications to fight such an infection will make it difficult to find a combination that will work successfully. Then, if John was to require CPR, which would probably cause several rib fractures, his pain would escalate further, and his pain management would become further deregulated. His present equilibrium would be destabilised. John's drug regime would have to be started over and there was no guarantee that the drug

regime which worked before his crisis would work again or work as well as it had been working prior to the crisis. This is, amongst other things, because the pain from the interventions would significantly exacerbate the dystonia thus requiring increased medication.

78. Important in this regard was Prof. D.'s evidence that he believes that John is likely to survive the next respiratory or other crisis, particularly if that crisis happens in the near future. In these circumstances the court must anticipate that John will likely experience a period of immense pain, probably of several weeks duration, following the use of any invasive measures with the possibility that such pain may never be brought fully under control. And that cycle will repeat itself at ever-decreasing intervals for as long as John can be kept alive.

79. As for the circumstances in which the clinicians considered it ethically appropriate to deliver intensive care to a patient, each stated that they considered that it was the role of the intensive care physician to treat a patient so as to provide them with a bridge to recovery. In this respect John's clinicians were unanimous in their belief that invasive measures should not be used to artificially prolong life where they would have the result which they will have if undertaken in the present case.

80. In particular, Dr F. stated that to use intensive care, which in itself is a traumatic process, to sustain John's life only to restore him to a condition where he would continue to experience suffering, distress and pain was ethically unacceptable. Given the choice of sustaining life versus trying to relieve suffering, the relief of suffering must be prioritised particularly when John can never make a meaningful recovery and will never be pain free.

81. All clinicians were agreed that in circumstances where John's parents were insisting that John should not be given a subcutaneous infusion on a continuous basis which might reduce his pain because it might precipitate a respiratory crisis, and where they were insisting that the hospital could not withhold the intensive therapies referred to at para.4 (ix) of the Notice of Motion if such a crisis were to arise, there was little possibility of John ever being

discharged to a regional hospital close to his home, or returning to live with his family. These would be goals to aim for if the approach proposed by the hospital was accepted by John's family. Regrettably, if invasive measures cannot be withheld John would have to stay close to ICU in a specialist children's hospital for the rest of his life.

Issues

82. As is evident from all that I have stated thus far, the hospital and John's parents are at odds over what is and is not in John's best interests. However, besides this issue, the dispute between John's parents and the hospital has raised a number of additional legal matters that must be resolved in this judgment.

83. Counsel for John's mother queries whether the exercise of the court's wardship jurisdiction is compatible with the constitutional rights of John's parents. Second, the court is asked to consider whether the constitutional prohibition of euthanasia prevents the hospital from seeking the relief set out in its Notice of Motion, as the orders sought, if granted and acted upon, may have the effect of shortening John's life. Third, it is argued that the case law previously applied to cases of this kind is not applicable in circumstances where the application has been brought so early in John's post-accident life and in circumstances where, it is asserted, John's prognosis is uncertain. Fourth, it is submitted that the application of the best interest test provides insufficient protection in this case. Finally, counsel for John's mother submits that there is no clear and convincing evidence available to justify the court exercising its jurisdiction.

84. In addition to adopting the submissions made on behalf of John's mother, counsel for John's father argues that the orders which the hospital seeks are unnecessary and should therefore not be granted. Counsel contended that the doctors are, in any event, entitled to

withhold ICU measures which they consider unethical. Thus, in light of the fact that the orders sought cannot be shown to be necessary, they should not be granted.

85. I will deal with these arguments in turn.

Can the Wardship Jurisdiction Be Exercised to Override the Wishes of the Parents?

86. In essence, the difficulty that I find myself in in this case is that, on the one hand, I am asked by John's parents to give John as long a life as possible in the hope that, in time, his condition will improve. Understandably, because of their profound love and deep devotion to John, they want everything that is medically possible to be done to sustain his life, thus maximising his opportunity for recovery. On the other hand, I am urged by those in charge of John's medical care, who have decades of experience between them, to grant the relief sought as, should a dystonic or other medical crisis present, it would be cruel to either withhold the subcutaneous medication necessary to bring his pain under control or subject him to invasive measures in ICU without which he might die. John's very poor outlook and devastating injuries, compounded by a strong likelihood that his dystonia will become deregulated in the event of invasive measures being deployed, must mean that, if a crisis arises, John should be given whatever medication he needs to bring his pain under control and that his life should not be artificially extended. In such circumstances, if necessary he should be allowed to die with dignity and with as little pain and suffering as possible.

87. Ordinarily when a court is confronted with a dispute such as this, the child is taken into wardship and the court, in consultation with the child's parents and the child's treating clinicians, will determine what is in the child's best interests. I will go into significantly more detail as to what is involved in this assessment later in this judgment. However, for the moment it is sufficient to say that in that scenario the court assesses the medical and family situation of

the child and then puts itself into the shoes of the child to determine what he or she would consider to be in his or her best interest ("the best interest test").

88. In this case, however, John's mother and father query whether the best interest test should be applied. They argue that the court cannot exercise its wardship jurisdiction as to do so would be an inordinate interference with their rights as parents as guaranteed by the Constitution. In particular, they maintain that Article 41.1 when taken in conjunction with Article 42A.2.1 must mean that the State can only interfere in those rare circumstances where it can be shown that parents have failed in their duty towards their children. In circumstances where they contend they have not failed in their duties, John's parents submit that the court cannot interfere with the decisions they have taken in respect of his care. Thus, they claim that the court cannot exercise its wardship jurisdiction and must not apply the best interest test.

89. In order to determine whether the court is entitled to exercise its wardship jurisdiction, I will first discuss the rights which the constitutional provisions relating to the family would appear to protect, as well as how and to what extent that protection is, in principle, achieved. I will then review how these considerations have been applied in previous cases where the medical treatment of children is concerned and how I believe they should be applied to the facts of this case. Finally, I will consider whether the wardship jurisdiction and the best interest test can be relied upon on the facts of the present case in light of the constitutional rights of the parties involved.

Constitutional Family Rights in General

90. Article 41.1 provides as follows:-

> "1 1° The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law.

2° The State, therefore, guarantees to protect the Family in its constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State."

91. Article 42A s. 1-2 provide:-

"1 The State recognises and affirms the natural and imprescriptible rights of all children and shall, as far as practicable, by its laws protect and vindicate those rights.

2 1° In exceptional cases, where the parents, regardless of their marital status, fail in their duty towards their children to such extent that the safety or welfare of any of their children is likely to be prejudicially affected, the State as guardian of the common good shall, by proportionate means as provided by law, endeavour to supply the place of the parents, but always with due regard for the natural and imprescriptible rights of the child.

2° Provision shall be made by law for the adoption of any child where the parents have failed for such a period of time as may be prescribed by law in their duty towards the child and where the best interests of the child so require."

92. It is well settled that Article 41.1 guarantees the collective rights of the family as an institution within society and as a consequence the State is obliged to protect the family unit in its constitution and authority. In order to fulfil these obligations, the State, in Article 41, agrees to cede control to the family in certain matters. In *Ryan v. Attorney General* [1965] I.R. 294, Kenny J., in the High Court, rejected the argument that the fluoridation of drinking water constituted a violation of Article 41.1.2° and made the following observation in relation to the rights which are protected by the provision. At pp. 308-309 he stated:-

"Not one of the counsel in this case has attempted to state what the inalienable and imprescriptible rights of the Family are and, as the Constitution gives little help on this,

I am in some difficulty in dealing with this argument. 'Inalienable' means that which cannot be transferred or given away while 'imprescriptible' means that which cannot be lost by the passage of time or abandoned by non-exercise. […] Some clue to the ambit of the rights of the family referred to in Article 41 is to be found in sub-s. 2 of section 1 where there is a reference to a guarantee by the State to protect the family in its constitution and authority. It seems, therefore, that the rights referred to in section 1, sub-s. 1, of Article 41 relate to the constitution and authority of the family. It was argued by the plaintiff's counsel that the addition of the fluoride ion to drinking water affected the authority of the family to decide what drink and food the members of the family should consume and that the Act of 1960 was, therefore, an attack on the authority of the Family. […] In my opinion, legislation dealing with the contents of food or drink does not in any way affect the authority of the Family and the Act of 1960 is not an interference with the rights guaranteed to the family by Article 41."

93. Regarding the rights protected by Article 41.1 of the Constitution, O'Donnell J. recently remarked as follows at para. 21 of his judgment in *Gorry v. Minister for Justice and Equality* [2020] IESC 55:-

"The rights guaranteed by Article 41.1.1° are therefore the correlative of the duties imposed upon the State by Article 41.1.2° to protect the Family in its constitution and authority: it is the right to establish a family unit and have an area within which the Family is in control. That area is not without both horizontal and vertical limits: first, the freedom of the Family, for example, within areas which might clearly be considered a family matter, such as decisions on the education of children, in the broadest sense, is not absolute. The Constitution expressly provides that the State may require basic standards of education. Similarly, there is a horizontal limit to what is within the authority of the Family. There are many things that a Family cannot decide or control.

There may indeed be significant contention as to where both the vertical and horizontal boundaries lie in any given case, but the structure of the Constitution is clear: it protects an area within which the institution of the Family is primarily in control and which is generally free from government or State interference […]"

94. It follows that one of the questions which I must answer in deciding this case is whether the decision by John's parents as to the care and treatment he should receive in the circumstances outlined in the hospital's application is, in principle, a family matter that falls within the ambit of protection afforded by Article 41. Then, if the answer to that question is in the affirmative, the second question that needs to be answered is how far the protection afforded by Article 41 actually goes. However, it is clear that the protection afforded to family affairs is not absolute and, in a case where the decision of parents might adversely affect their child, there is clearly a tension between the parental rights and the rights of the child. So, whilst on the one hand the State is under an obligation to respect the family, and by extension the decision of the parents, on the other hand it is obliged to vindicate and protect the constitutional rights of every person including the child.

95. But, what is not clear is the point at which the court may interfere to resolve these competing constitutional rights. Article 41 itself is silent as to where the constitution draws the line. Given that in Article 41.1.2 the state guarantees to protect the family in its constitution as well as authority, we are told that this unit must be protected from external forces. What we are not told is in what circumstances that protection can be lost.

96. What is nonetheless clear is that almost any exercise by parents of their Article 41 rights have the effect of curtailing, to varying degrees, the rights of the child and that if the courts were to step in at every turn where it could be shown that the rights of the child were being, or might in the future be adversely affected, the parental rights would be entirely undermined. It is for this reason that the courts, in a series of cases, have concluded that the rights of the child

must be presumed to be vindicated by the actions or inactions of their parents unless that presumption can be rebutted.

97. This presumption was first considered in *In re J.H. (an infant)* [1985] 1 I.R. 375, a case which concerned the adoption of a child put up for adoption by its mother shortly after birth. The child's parents were separated at that time but after four years they married and sought to resist the adoption of the child by its foster parents. It was accepted, albeit in the context of s.3 of the Guardianship of Infant's Act 1964, that in deciding whether to allow or refuse the adoption, the best interests of the child were paramount. At p. 383 Finlay C.J. commented:-

> "I would, therefore, accept the contention that in this case s. 3 of the Act of 1964 must be construed as involving a constitutional presumption that the welfare of the child, which is defined in s. 2 of the Act in terms identical to those contained in Article 42, s. 1, is to be found within the family, unless the Court is satisfied on the evidence that there are compelling reasons why this cannot be achieved, or unless the Court is satisfied that the evidence establishes an exceptional case where the parents have failed to provide education for the child and to continue to fail to provide education for the child for moral or physical reasons."

98. The grounds considered sufficient to rebut the presumption, which were initially discussed in the context of a failure on the part of parents to provide education for their children, have since been extended to cases other than those concerned with education. In *North Western Health Board v. H.W.* [2001] 3 I.R. 622, the parents of a new-born child objected to a heel pin prick test being carried out on their child. The test was minimally invasive but could be used to diagnose an array of diseases which, although rare, if left untreated would have devastating consequences and could even be fatal. The hospital had invoked the court's inherent jurisdiction to obtain permission to carry out the test. By a 4-1 majority, the Supreme Court

held that the State could not interfere with the wishes of the parents. Hardiman J. observed the following at paras. 402-403:-

> "This constitutional provision [Article 42.5] was considered in *In Re Article 26 of the Constitution and the Adoption (No.2) Bill 1987*. The court held that:-
>
> > "Article 42.5 of the Constitution should not, in the view of the Court, be construed as being confined, in its reference to the duty of parents towards their children, to the duty of providing education for them. In the exceptional cases envisaged by that Section where a failure in duty has occurred, the State by appropriate means shall endeavour to supply the place of the parents. This must necessarily involve supplying not only the parental duty to educate but also the parental duty to cater for the other personal rights of the child".
>
> […]
>
> It appears, on the basis of the last quotation, that Article 42.5 is broad enough in its terms to cover the range of parental duties, and not merely those relating to education. This being so, it appears that the presumption that the welfare of the child is to be found in the family exercising its authority as such is equally broad in its scope and that any rebuttal or displacement of it will normally involve invocation of the provisions of Article 42.5."

99. However, in that case, the court also made broader observations as to the circumstances in which the presumption might be rebutted. Denham J. noted at paras. 238-239 of her judgment:-

> "The decision in this case requires the correct constitutional balance between the responsibility of the parents and the health board and the constitutional rights (family and personal) of the child. The fundamental principles by which the community wishes to live are to be found in the Constitution. The Constitution clearly places the family as

the fundamental unit of the State. The family is the decision maker for family matters - both for the unit and for the individuals in the family. Responsibility rests fundamentally with the family. The people have chosen to live in a society where parents make decisions concerning the welfare of their children and the State intervenes only in exceptional circumstances. Responsibility for children rests with their parents except in exceptional circumstances. In assessing whether State intervention is necessary the fundamental principle is that the welfare of the child is paramount. However, part of the analysis of the welfare of the child is the wider picture of the place of the child in the family; his or her right to be part of that unit. In such a unit the dynamics of relationships are sensitive and important and should be upheld when possible as it is usually to a child's benefit to be part of the family unit.

In seeking the balance to be achieved between the child's rights within and to his family, and the family (as an institution) rights, and the parents" right to exercise their responsibility for the child, and the child's personal constitutional rights, the threshold will depend on the circumstances of the case. Thus, if the child's life is in immediate danger (e.g. needing an operation) then there is a heavy weight to be put on the child's personal rights superseding family and parental considerations."

100. At para. 245, Denham J. proceeded to echo what Finlay C.J. said in *J.H.*:-

"There is a constitutional presumption that the welfare of a child is to be found within the family unless there are compelling reasons why that cannot be achieved or unless there are exceptional circumstances where parents have failed to provide education for the child: *In re J.H. (an infant)* [1985] I.R. 375. It is not suggested that the child be removed from the defendants in this case; the child will remain within the family no matter what the decision. However, any intervention by the courts in the delicate filigree of relationships within the family has profound effects."

101. In *N. v. HSE* [2006] IESC 60, Hardiman J. gave a succinct explanation for the presumption. He noted at para. 148:-

> "I do not regard the constitutional provisions summarised above, or the jurisprudence to which they have given rise, as in any sense constituting an adult centred dispensation or as preferring the interests of marital parents to those of the child. In the case of a child of very tender years, as here, the decisions to be taken and the work to be done, daily and hourly, for the securing of her welfare through nurturing and education, must of necessity be taken and performed by a person or persons other than the child herself. Both according to the natural order, and according to the constitutional order, the rights and duties necessary for those purposes are vested in the child's parents. Though selflessness and devotion towards children may easily be found in other persons, it is the experience of mankind over millennia that they are very generally found in natural parents, in a form so disinterested that in the event of conflict the interest of the child will usually be preferred […]
>
> There are certain misapprehensions on which repeated and unchallenged public airings have conferred undeserved currency. One of these relates to the position of children in the Constitution. It would be quite untrue to say that the Constitution puts the rights of parents first and those of children second. It fully acknowledges the "natural and imprescriptible rights" and the human dignity, of children, but equally recognises the inescapable fact that a young child cannot exercise his or her own rights. The Constitution does not prefer parents to children. The preference the Constitution gives is this: it prefers parents to third parties, official or private, priest or social worker, as the enablers and guardians of the child's rights. This preference has its limitations: parents cannot, for example, ignore the responsibility of educating their child. More fundamentally, the Constitution provides for the wholly exceptional situation where,

for physical or moral reasons, parents fail in their duty towards their child. Then, indeed, the State must intervene and endeavour to supply the place of the parents, always with due regard to the rights of the child."

102. From the aforementioned case law, the general principles in relation to the presumption that the welfare of the child is to be found within the family and the decisions made by parents in that context, can be summarised as follows. First, in acknowledgment and in vindication of the constitutional rights of the parents, the court should presume that the best interests of the child are best served within the family and for that reason must not unduly interfere with the affairs of the family. Second, only where there are compelling reasons or where there is a dereliction of duty on the part of the parents can the courts intervene with family matters. It should also be noted that, as is apparent from the *dictum* of Hardiman J. in *North Western Health Board*, this principle is based upon the analogous application of the provisions previously found in Article 42.5 of the Constitution to family rights derived elsewhere under the Constitution. Finally, in any balancing of the parental rights and the rights of the child, the best interests of the child are paramount.

103. Before applying the aforementioned principles to the facts of the instant case, I should briefly mention how the constitutional amendments, i.e. those brought about by the introduction of Article 42A and the deletion of Article 42.5, may have altered the constitutional position.

104. In principle, it could be argued that the changes to the Constitution have moved the point at which the State may seek to interfere with parental rights. Regrettably, none of the four parties to this application addressed the significance of these developments. Nonetheless, I think it would be unsatisfactory if I did not make a few observations regarding the changed landscape.

105. First, Article 42A.1 now explicitly makes reference to the rights of the child. On the one hand, it might be said that the explicit reference to the child should be taken to bolster the proposition that children are now to receive greater immediate protection from the State. On the other hand, given that the rights of the child were previously recognised by the court, be that under Article 41 or Article 40, it might be stated that Article 42A.1 does no more than merely restate rights already acknowledged to exist.

106. Second, Article 42A.2.1° although formulated in similar terms to that of Article 42.5, may now have taken on a different colour in light of the structural changes that have occurred. On a plain reading, it is not unreasonable to assume that the provision was primarily intended to provide the child with the right to demand that the State would interfere to protect its rights where their parents had failed in their duty, unlike, Article 42.5, which was interpreted to provide parents with the right to limit State interference with decisions made concerning their children. Naturally, the argument can be made that the latter is the natural consequence of the former, i.e. the right of the child for State interference in certain circumstances necessarily includes a right of the parents not to be subjected to State interference unless those circumstances are present, but it is not immediately obvious why this should be so.

107. Furthermore, even prior to the constitutional amendments, the application of Article 42.5 to Article 41 was on a rather narrow footing. The text of the constitution did not indicate that Article 42.5, which was embedded within Article 42, was to be applied to Article 41. In *North Western Health Board*, one justification proffered for this application was that Article 42.5 is "*broad enough in its terms*" to justify application in the context of Article 41. But, to what extent the "breadth of the terms", contrary to the explicit words used, justifies application of the provision in the context of another right is not immediately evident. Moreover, the structure and text of the Constitution in Articles 41 and 42 did not indicate that the framers of the Constitution intended that the provision of one article should be applied to another. Now,

with the constitutional changes, the approach of applying the limitations formerly listed in Article 42.5 in the context of Article 41 may be fatally undermined. Nevertheless, given the small differences between Article 42.5 and Article 42A.2.1° and the unaltered Article 41, I feel bound by the decision in *North Western Health Board* to construe Article 42A.2.1 as limiting State interference, as proposed by counsel for John's mother.

Is the Decision in Principle a Family Matter and Is the Presumption Rebutted?

108. In *North Western Health Board*, the court accepted that a decision by parents about whether their child should be subjected to a screening test was a family matter. But, that case was brought under the court's inherent jurisdiction and, further, it was accepted that the circumstances would have been different if the court's wardship jurisdiction could have been invoked. Murray J. observed at para. 286:-

> "If this court was exercising a *parens patriae* jurisdiction and stood in *loco parentis* to the child such as would arise if he was a ward of Court then the Court would be free to decide whether the child should be subjected to a P.K.U. test on the basis of what a prudent and responsible parent would do in the interest of the child. Since the Court does not exercise such a jurisdiction in this case, this approach is not open to it."

109. Likewise, in *In re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 I.R. 79, Hamilton C.J. made similar comments. *In re a Ward of Court* the mother of an adult ward, in her capacity as committee of the ward, sought directions as to the ward's medical treatment. At the time the ward had been in a minimally conscious state for over 20 years and her mother applied to the court to ask for an order that the life-sustaining treatment be withdrawn. She put forward a similar argument to that of John's parents in the present case arguing that her parent wishes were protected under the Constitution and must not be interfered

with except in exceptional circumstances. Hamilton C.J. made the following observation at pp. 163-164:-

> “The family
>
> The family is the basic unit group of society, its special position in our community is recognised by the Constitution. Article 41, s. 1 states:
>
> "1 The State recognises the Family as the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law.
>
> 2 The State, therefore, guarantees to protect the Family in its constitution and authority, as the necessary basis of social order and as indispensable to the welfare of the Nation and the State".
>
> This case concerns a ward of court and so the jurisdiction to make the decision in this situation lies with the court and not the family. The mother of the ward is the committee of the ward and her view is shared by the entire family. The family's view as to the care and welfare of its members carries a special weight. A court should be slow to disagree with a family decision as to the care of one of its number if that decision has been reached *bona fides* after medical, legal and theological advice and careful consideration.
>
> In this case, the family is united in its view of what decision should be made. While that view does not determine the issue before this Court it is a factor to which the Court should give considerable weight.
>
> The core of this case concerns personal rights. The personal rights of the ward. Article 41, on the other hand, has to do with the institution of the family. As Costello J. said in *Murray v. Ireland* [1985] I.R. 532 at p. 537 (having considered the judgment of Kenny J. in *Ryan v. Attorney General* [1965] I.R. 294):

". . . the rights, in Article 41, s. 1, sub-s. 1, are those which can properly be said to belong to the institution itself as distinct from the personal rights, which each individual member might enjoy by virtue of membership of the family. No doubt if the rights of the unit group were threatened or infringed, any member of the family could move the court threat to the rights granted to the unit, and not to those of its individual members."

At issue in this case are the personal rights of the ward: not the rights of the fundamental unit group of the State. Thus, it is a matter which falls to be decided as a matter of personal rights rather than under Article 41."

110. Thus, the authorities suggest that where the wardship jurisdiction is exercised, the matter is no longer a family matter and it falls to the court to determine what is in the child's best interests. But, in her oral submissions, counsel for John's mother pointed to a passage in *Kelly: The Irish Constitution* (5th ed, 2018) where its authors remark that there is no principled justification for treating a child brought into wardship and a child where medical treatment is sought pursuant to the court's inherent jurisdiction differently. Although this point was not expanded upon by counsel in argument or by the authors of *Kelly* what I assume they mean is that both the inherent jurisdiction and the wardship jurisdiction must be exercised in accordance with the Constitution and, as a consequence, constitutional rights must be vindicated equally, regardless of which jurisdiction is invoked. Accordingly, it is argued on behalf of John's parents that even where the wardship jurisdiction is invoked, as is in the present case, their rights must be respected in the same way as if John had not been taken into wardship.

111. I have to say that I have found the differing approaches in the case law, depending upon whether or not the court's wardship jurisdiction is invoked, difficult to reconcile. However, on a close analysis of the relevant authorities, I am satisfied that John's parents are correct in their assertion that the State simply cannot have recourse to the wardship jurisdiction to escape the

limitations otherwise imposed upon it by the Constitution. As touched upon earlier, the presumption that the welfare of the child is to be found within the family and the decision made by their parents in respect of their care, unless that presumption has been rebutted, prevents the State from unduly interfering with the affairs of the family.

112. In my view, the decision in *In re a Ward of Court* can be distinguished from the facts in this case on the basis that the child in that case was already a ward of court with the result that the court clearly stood in *loco parentis* vis-à-vis the ward at the time the dispute between the hospital and the ward's mother arose. Once the child in question is a ward of court the court has the jurisdiction to make the decision for the child. However, here the dispute between the hospital and John's family occurred before the court's wardship jurisdiction was engaged. Furthermore, John's parents objected to the court taking John into wardship in circumstances where they were fully meeting their obligations as parents. In these circumstances the court is in a very different position to that which it would be in if dealing with a child to which it had been in *loco parentis* for many years.

113. In my view, on the facts of this case I am satisfied the court cannot really claim to be in *loco parentis* to the ward when the fact of the matter is that the principle reason it was asked to take John into wardship was to find a suitable forum within which the dispute between the hospital and John's parents might be resolved with all due expedition. It, therefore, follows that the reasoning in *North Western Health Board* applies with equal force in this case as it applied to the court's inherent jurisdiction. What this means is that, in principle, it is a matter for John's parents to make the decision concerning his medical treatment. The fact that the wardship jurisdiction has been invoked does not distract from their rights as parents to make such decisions without undue interference by the State.

114. This is not to say that there may not be circumstances where a decision regarding the medical treatment of a child are, even without considering the presumption, not a family matter.

For example, where the parents of a child disagree about the treatment to be pursued or where the child, although still a minor, is, in the eyes of the law, capable of consenting to certain treatment and does so contrary to the wishes of its parents, the decision may presumptively not be a family matter. However, in John's case, the right to make the decision regarding his medical treatment is, in principle, one for his parents to make.

115. I will now consider whether the presumption in favour of protecting the parental rights enjoyed by John's parents to make the decision regarding his medical treatment has been rebutted. As discussed, the Constitution does not offer unlimited protection to those rights and the State is permitted to interfere where it can no longer be presumed that the interests of the child are best served within the family.

116. As I have already observed, the State may interfere with family matters where there are compelling reasons to do so or where it is established that the parents have failed in their duty. I pause here to observe that counsel for John's mother contended that the court can *only* interfere where the actions or inactions of the parents amount to dereliction of the duties which they owe to their child. However, the problem with that argument is two-fold. First, it is not supported by the authorities. In *J.H.* and in *North Western Health Board*, the court explicitly stated that the State can also interfere where there are compelling reasons for doing so, outside the circumstances of dereliction of duty.

117. Second, the approach proposed by counsel for John's mother is not borne out by the Constitution. The Constitution makes clear that the State must be in a position to step in, even in the absence of any failure on the part of the parents. The constitutional rights of the child, although presumed to be vindicated by any decision made by their parents concerning their care, are not held in abeyance. The State cannot put on blinkers and only look at whether there has been a failure on the part of one person to determine whether the rights of another person deserve protection. Where it can be shown that the rights of the child are in serious jeopardy,

it is no longer safe for the court or the State to rely upon the presumption that the child's imprescriptible rights will be vindicated by their parents. Where there are compelling reasons to believe that the child's imprescriptible rights will not be protected or vindicated by their parents, the State must intervene to fulfil its obligations towards the child. Were that not the case, the rights of the child could be set at nought. Further, it is important to stress that before a court may intervene to protect and vindicate the rights of the child it is not appropriate for it to find that the course of action taken by the parents is not in the child's best interests. What is required is that it be established that the rights of the child are so clearly and materially in jeopardy that the court must make sure that, whatever decision is made, it is the one that vindicates the child's constitutional rights.

118. Accordingly, what I must now decide is whether it has been established that John's rights are so clearly and materially in jeopardy that there are compelling reasons to conclude that the presumption is rebutted.

119. To answer the first of the aforementioned questions, it is important to state that "dereliction of duty" within the meaning of Article 42.5 has been interpreted to be an objective standard. In *In re a baby A.B.* [2011] IEHC 1 the court was concerned with an emergency application brought by a hospital to administer a blood transfusion to an infant. The parents had objected on religious grounds. Hogan J. remarked at para. 37:-

> "Of course, in one sense - as Birmingham J. pointed out in a case with very similar facts, *Re Baby B*, High Court, 28th December, 2007 - the use of the term "failure" in this context is perhaps a somewhat unhappy one, since there is no doubt but that CD and EF, acting by the lights of their own deeply held religious views, behaved in a conscientious fashion vis-à-vis Baby AB. The test of whether the parents have failed for the purposes of Article 42.5 is, however, an objective one judged by the secular

standards of society in general and of the Constitution in particular, irrespective of their own subjective religious views."

120. Consequently, the question that I must ask myself is whether the position John's parents have adopted in relation to his medical care can objectively be classified as a failure of their duty as parents. Although I have not come to this decision lightly, in my opinion, their actions must be so considered.

121. First of all, it must be stated that the wishes of John's parents are undoubtedly born out of the extent and ferocity of their love for John. It is wholly understandable for any parent who loves their child as much as they do to be instinctively drawn to making decisions which will prolong their child's life. However, in this case, their love of John, has, in my view, rendered them incapable of acknowledging the fundamental truth as to his condition and handicapped them in their capacity to vindicate his rights.

122. The court has heard detailed and uncontradicted evidence that the invasive measures sought to be withheld would have a devastating effect not only on John's condition but on what he will endure in his life thereafter. He would be subjected to significant physical trauma in the course of such treatment and his dystonia would likely become deregulated leading him into a period or periods of very significant pain. And, John's parents simply refuse to accept that the invasive measures his clinicians want to withhold will not bridge John to a life with a better outlook but will only expose him to a life of further suffering and place him on a poorer health trajectory than that which he was on before those measures were deployed.

123. Second, the only reasonable explanation for John's parents refusing to permit his clinicians give him the subcutaneous medication he might need to bring his pain under control should he develop a dystonic crisis, must be that their desire to extend his life has blinded them to the enormity of the pain that he has thus far suffered from his dystonia and will have to endure in the future in the event of a dystonic crisis. The uncontradicted evidence was that a

dystonic crisis would produce pain of the type and duration that John had only once ever previously experienced. To put that type of pain in context, it is worthwhile noting that John's clinicians referred to what I will call his routine dystonic pain in the months preceding this application as cruel, with Dr W. referring to it as the second most severe she had seen in over 9 years working in Great Ormond Street Hospital where she treated large numbers of patients with this condition. And the uncontradicted evidence was that pain from dystonia leads inexorably to an increase in the frequency and severity of dystonic episodes. Yet John's parents refuse to let the clinicians intervene to medicate him if there is any risk he might as a result develop respiratory distress and might as a result possibly die. They have decided he must remain in pain should he meet a dystonic crisis. No reasonable parent understanding the consequences of their child experiencing a dystonic crisis of the type anticipated in this case could reasonably make such a decision.

124. Perhaps, another reason why John's parents refuse to give consent to John's clinicians to treat him with a subcutaneous infusion should he develop a dystonic crisis is because John himself, because of his disabilities, is simply unable to cry out and implore them to ask the doctors to alleviate his pain.

125. Regrettably, I have formed the view that the decisions that John's parents are making, objectively assessed, are based upon an entirely false premise as to what John has endured to date and what his prognosis in the future will be following either a dystonic crisis, which might require a subcutaneous infusion to alleviate his pain, or a crisis that would take him to the doors of the ICU where he would need invasive measures to survive. In their failure to acknowledge John's condition and likely prognosis in either situation, they are failing in their duty as parents to vindicate the rights which he, because of his age and injuries, cannot himself protect. John has a right, and his parents, the duty, to make a fully informed assessment of his circumstances,

in particular where the effects of any decision that they make regarding either situation will be so grave and pressing for John.

126. Furthermore, the consequences for John of the wholly unreasonable and unsubstantiated view that his parents take of what will happen to him as a result of the implementation of their decisions in the two alternative scenarios discussed above provides compelling reasons as to why the court must now step in to vindicate his rights.

127. Relevant in this regard is the fact that this case is readily distinguishable from *North Western Health Board* in that the threat to John's rights is much more concrete and real than it was to the child in that case. Here, there is considerably more certainty that the decision of the parents will have an adverse and significant effect upon John. Any decision made will materially affect the life John will live, the pain he will endure and the sacrifices he will be expected to make. In *North Western Health Board*, there was only the remotest chance that the infant concerned would have any of the diseases that the screening sought to diagnose.

128. In addition, I am convinced that there are compelling reasons beyond those already discussed that demonstrate that John's best interests cannot be achieved within the family. As detailed above, the court has heard from an array of expert paediatricians and paediatric intensivists that the decision taken by the parents will have seriously adverse effects upon John's life. I reject the argument that John's prognosis is in any material respect unclear or uncertain. There is as much certainty as there can be with any medical diagnosis that John will not recover in any significant way from his injuries. The brain scans show severe diffuse brain damage which will never heal. Both paediatric neurologists were very explicit about that. And, John will have all of the limitations, physical and intellectual, discussed in the course of this judgment. Furthermore, Dr G. also said that ICU invasive measures will deregulate John's dystonia treatment and will, in all likelihood, lead to a resurgence of his dystonia and the pain that comes with it. And, if for some reason John was to develop a dystonic crisis, the evidence

as to the pain he would endure, absent subcutaneous infusion, is simply unimaginable and would never be accepted by any reasonable person capable of making decisions in respect of their own welfare.

129. In circumstances where John's rights are under such strain, the State cannot stand idly by. No constitutional right can be used to inflict such grievous suffering upon one person. This is not to say that John's parents do not deeply care for John. It could not be further from the truth to say so. Regrettably, I am satisfied that it is the extent of their devotion and love for John that has left them incapable of stepping in to vindicate his rights.

130. Before concluding my thoughts on this issue, a number of final observations should be made. First and foremost, nothing I have said in relation to the constitutional rights of John and his parents mean that the views of John's parents will not be at the forefront of my mind when determining where John's best interests lie. As will be explained later, their evidence as to what John would choose were he in a position to make a choice has materially influenced the view I have taken of this case. However, John's rights are the more pressing concern here.

131. Second, in the case law the concern is repeatedly expressed that State intervention in family affairs risks the creation of an overbearing State which might meddle with family affairs which the Constitution has sought to protect. Whilst, in principle, this is a legitimate concern, in my view, the safeguards the constitution provides are sufficient to guard against any State overreach in such matters. Furthermore, an argument of this kind is, in a case such as that under consideration here, something of a red herring. State intervention in this case needs to be seen in its proper context. Cases like this are extremely rare. In almost all instances, the hospital is able to come to an agreement with the child's parents as to how their future care or treatment should be managed. Multiple witnesses testified that this is the first time they had been involved in litigation of this kind in Ireland. What this means is that the State intervention is also very

rare. The overwhelming majority of decisions regarding the medical treatment of children are resolved without recourse to State intervention.

132. Lastly, I would like to add that any application such as the one brought in these proceedings by the hospital should only be entertained where there is no doubt that the hospital has done everything reasonably possible to convince the child's parents of their point of view. To respect the rights of the parents, a hospital needs to demonstrate that it has taken every reasonable step and availed of every opportunity to reach agreement with the parents. In this case, the court had a wealth of evidence concerning the efforts made by the hospital to reach an agreement regarding John's future care with his parents. Indeed, one witness stated that a point had been reached where it was unfair of the clinicians to consistently and repeatedly ask parents to change decisions that they had made concerning their child.

133. For these reasons, I am satisfied that the parental rights derived from article 41.1 of the Constitution do not preclude State intervention in this case. However, the question remains as to whether the wardship jurisdiction and the best interest test provide a suitable means by which this is done. Because there is a risk of repeating myself, I will address this issue in the section of this judgment where I discuss whether the case law that gave rise to the best interest test should be applied. However, a point that can be addressed at this stage is that which was contended for by counsel for John's mother. She maintained that if State intervention is constitutionally permitted, it must be by way of statute and in support of her submission she relied upon several passages from the decision in *North Western Health Board*, where the court intimated that this must be so.

134. Hardiman J. had perhaps the most detailed engagement with this issue. At pp. 761-762 he remarked:-

> "I would however, observe that in a case such as the present it is particularly desirable from every point of view that any initiative to compel parents to subject their children

> to a test such as P.K.U. be based on statute law and not on an application such as the present. I am expressing no view whatever as to whether such legislation would be desirable or otherwise. But if it were thought that a parent should be deprived of a right to refuse to consent to the P.K.U. test, or any test, inoculation, examination, or procedure, that would be a major departure in public policy. The legislature, and not the courts, are in the best position to judge whether such an innovation is necessary, proportionate or desirable, whether there are countervailing considerations of a social or medical nature or otherwise; whether there exists sufficient consensus in the community to make legislation feasible or desirable and many other relevant considerations. Compulsory medical diagnosis or treatment in any form is, for the reasons identified in the judgment of the learned Chief Justice, a topic regarded with some unease throughout the civilised world. The degree to which this unease should be recognised, whether precautions can be taken to allay legitimate fears, and the fundamental question of whether the imperative behind the P.K.U. test or any other test is sufficient to justify coercion, are all matters best addressed legislatively."

135. What becomes obvious from this passage is that the reason for imposing this restriction is something not found in the present case. In *North Western Health Board*, granting the relief sought by the hospital, to carry out the heel pin prick test, would have meant that the test would become effectively compulsory for every child. This type of decision is best reserved for the Oireachtas and therefore, the court observed that a decision of this kind cannot be made without statute. Here, this complication does not arise. The relief sought by the hospital will not transcend the boundaries of this case. It is solely aimed at John's peculiar circumstances and will not have any effect upon policy or similar cases.

Accelerating Death

136. Before I engage with the wardship jurisdiction in detail, I have to address the point raised by Senior Counsel for John's mother, Ms. Siobhan Phelan S.C., that the relief sought in para. 4 of the Notice of Motion in effect amounts to a permission in favour of the hospital to accelerate John's death. She refers in particular to the subcutaneous infusion of dystonia medication which may have as its side-effect to suppress respiratory function. This, as a matter of constitutional law, she contends, is impermissible. In support of her argument Ms. Phelan principally relies upon a passage from *In re a Ward of Court* in which Hamilton C.J. said as follows at p. 124:-

> "As the process of dying is part, and an ultimate, inevitable consequence, of life, 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."

137. At this point, I feel that it is important to say a few words about paediatric palliative care which may assist in characterising the relief sought by the hospital.

138. In the course of this case I had extremely helpful and thought-provoking evidence from Dr M., who, as already stated, is a specialist in paediatric palliative medicine. Dr M. explained that children's palliative care is designed to embrace the physical, emotional, social and spiritual care of the child whilst also providing support to their family. It can last for days, weeks, months and sometimes years. And, I have to say I was somewhat surprised to hear from

Dr M., that the statistics suggest that if a patient has palliative care at the end of their life they are likely to live longer than they might otherwise have lived but for the introduction of that care.

139. To qualify for palliative care a child must have a life-limiting condition or it must be shown that the child would benefit from a holistic and total active approach to their care. The primary focus of a palliative care specialist is on the child's symptoms. The intent of palliative care is never to shorten life, its goal is to relieve suffering and keep the child living well for as long as possible whilst providing care that will give them the potential to die well, given that death is a normal part of life. Children receiving palliative care are continually reassessed and re-evaluated and are given the medication they need to keep them comfortable. This is why I am told it is so important that a programme of palliative care be put in place to run parallel with John's other clinical care. The clinicians wish to enhance John's quality-of-life without compromising on quality for the sole purpose of sustaining life.

140. In John's case, the hospital is seeking permission to administer strong pain-killing medication via subcutaneous infusion in the event that a dystonic crisis cannot be brought under control with less drastic measures.

141. Two observations may be made in relation to this issue. First, it must be acknowledged that decisions regarding the administration of intense pain-relieving medication which has as its side-effect that breathing or another vital function is suppressed are made every day in hospitals around the country. And, as was made clear in this case, all of John's medications, not only that which might be delivered by subcutaneous infusion, have the potential to depress his respiratory reserves because sedation has the effect of relaxing his body and reducing his ability to cough and clear his secretions.

142. Second, it is important to properly characterise the relief sought. It is not what in common parlance is often referred to as "euthanasia" if one understands euthanasia to mean

the preventative killing of a person who is terminally ill so that he or she will not suffer a painful death. The subcutaneous infusion under discussion in this case would only ever be given as a response to pain of the enormity earlier discussed in an effort to reduce that pain and not given to terminate life so that that pain never manifests itself. Another way of putting this would be to say that the relief the hospital is seeking is not to cut short John's life in anticipation of his eventual demise, but, in circumstances where John has a dystonic crisis, the medication then administered in response to that specific crisis may have the effect of terminating his life. No one is suggesting that the hospital be given liberty to terminate John's life because he may experience pain in the future.

143. As was made clear by Dr M.'s evidence, the aim of palliative care is never to shorten life and the subcutaneous infusion of strong painkilling medication is not to be used to cut short John's life at the discretion of the hospital. But, in an effort to control any acute pain John may suffer, the medication administered may, as a secondary effect suppress his breathing. This approach chimes with the comments made by Hamilton C.J. in *In re a Ward of Court*. John's right to life is vindicated where, in an effort to provide him with a pain-free life, he is given a dignified death.

Applicability of Previous Case Law and the Wardship Jurisdiction

144. Next, counsel for John's mother argued in the alternative that the case law previously applied to cases of this kind does not operate in John's case. She contends that because the application has been brought so soon after the accident and there is no settled diagnosis, this court cannot apply the test it normally applies. To do so, counsel argues, would amount to an inordinate extension of the court's wardship jurisdiction as well as a failure to adequately protect and vindicate John's right to life or the parents' constitutional rights. She argues that

the facts of this case are "unprecedented" and that the safeguards offered by the existing case law are insufficient to protect John's rights in the circumstances.

145. To understand why John's mother's contention regarding the existing case law must fail and to understand why the wardship jurisdiction is applicable in the instant case, it is important to acknowledge the objective of the wardship jurisdiction and to understand, in light of that objective, how and why the courts have applied the best interest test in the past in cases of this kind.

146. As is echoed throughout the case law, the wardship jurisdiction exists to vindicate and protect the rights, constitutional or otherwise, of the ward. In a passage often cited in wardship cases in *In re a Ward of Court* Hamilton C.J. observed at p. 126:-

> "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 [...] 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."

147. Therefore, a declaration of wardship never has the effect of depriving the ward of their rights. Such a declaration is made only in recognition of the fact that the ward can no longer exercise these rights due to their mental incapacity. In the hands of the ward the right would be inexercisable and therefore lost. With the State being under an obligation to vindicate and protect those rights, it falls to its organs to do so. By virtue of s. 9 of the Courts (Supplemental Provisions) Act 1961, that duty has been vested in the President of the High Court or any other High Court judge as the President may from time to time determine. It follows that the wardship jurisdiction exercised by the courts exists, not to take rights away, but to vindicate those rights where the ward cannot do so themselves. All rights continue to be vested in the ward, it is only

that another has to look after those rights as the ward, in his or her present condition, is unable to do so.

148. This objective, to vindicate rights, is preserved in the test that is applied in an application to determine what medical treatment a ward of court should receive. In cases where the ward has a life-threatening condition or where medical treatment is likely to have an adverse impact upon the ward's life, it is his or her constitutional right to life that takes centre stage in such deliberations. In essence, the court must ask itself how best to vindicate and protect the ward's right to life, in circumstances where the court cannot ask the ward what his or her wishes would be and where he or she has given no explicit instructions.

149. First, in light of the constitutional protections of the right to life and in acknowledgement of the sanctity of life, there is a strong presumption in favour of life-sustaining or life-saving treatment. For example, in *In Re S.R. (a Ward of Court)* [2012] 1 I.R. 305 at 323 Kearns P. held: *"[i]t is accepted that, given the importance of the sanctity of human life, there exists in circumstances such as in the present case a strong presumption in favour of authorising life-saving treatment*". Similarly, in *H.S.E. v. J.M. (a Ward of Court)* [2017] 1 I.R. 688 at 713 Kelly P. observed the following:-

> "'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. in *In re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 I.R. 79 at p. 123).
>
> There exists a 'constitutional presumption that the ward's life be protected' (per Denham J. in *In re a Ward of Court (withholding medical treatment) (No. 2)* [1996] 2 I.R. 79 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)* [2011] EWHC 2443 (Fam.), [2012] 1 W.L.R. 1653 at p. 1687 where he said:-

> 'The first principle is the right to life. As Lord Goff observed nearly 20 years ago in [*Airedale N.H.S. Trust v. Bland* 714 H.C. [1993] A.C. 789 at p. 863], 'the fundamental principle is the principle of the sanctity of human life'. Munby J. in [*R. (Burke) v. General Medical Council* [2004] EWHC 1879, [2005] Q.B. 424, at para. 213(o), p. 495] 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.'"

150. However, to vindicate the right to life does not equate to doing everything medically possible to sustain life or to ensure survival at all costs. In *In re a Ward of Court* it was recognised that to vindicate the right to life may mean to choose dignity in life and dignity in death over survival. At p. 124 Hamilton C.J. said:-

> "As the process of dying is part, and an ultimate, inevitable consequence, of life, the right to life necessarily implies the right to have nature take its course and 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."

151. This concept was perhaps more succinctly put by the trial judge (Lynch J.) in the same case, in words which were endorsed by O'Flaherty J. on appeal at p. 134 of his judgment:-

> "Death is a natural part of life. All humanity is mortal and death comes in the ordinary course of nature and this aspect of nature must be respected as well as its life-giving aspect. Not infrequently, death is welcomed and desired by the patient and there is nothing legally or morally wrong in such an attitude. A person has a right to be allowed

to die in accordance with nature and with all such palliative care as is necessary to ensure a peaceful and dignified death."

152. These observations demonstrate why the presumption in favour of life-sustaining treatment is a presumption and not a hard and fast rule, albeit a strong presumption. It may be rebutted. Departure from it is justified where the court is satisfied that granting the relief sought is in the best interests of the ward. More specifically, the court must be convinced that the treatment proposed by the hospital is in the best interests of the ward, as subjectively assessed. I will pause here to say that I hope that John's mother and father understand what I mean when I say that John's best interests must be subjectively assessed. By that I mean that I must ask myself what John would decide was in his best interests if he was able to view himself in the circumstances he is presently in and was able to make a reasoned and informed decision as to how he would like his condition to be managed. *In Re S.R. (a Ward of Court)* another case concerned with a minor, Kearns P. expressed it as follows in a passage cited and applied by Kelly P. in *J.M.*, at para. 55 (p. 323 of the report):-

> "[...] I agree with the views expressed by Lord Donaldson M.R. in *In re J. (Wardship: Medical Treatment)* [1991] Fam. 33 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."

153. To appreciate why the test is subjective is important in understanding why the courts have applied the best interest test to cases of this kind. The reasons behind this were perhaps best encapsulated by McKenzie J. in a decision of the Supreme Court of British Columbia in *In re Superintendent of Family & Child Service and Dawson* (1983) 145 D.L.R. (3d) 610 quoted by Lord Donaldson M.R. in *In re J. (A Minor) (Wardship: Medical Treatment)* [1991]

Fam. 33 which, although not made under the confines of the Constitution, apply equally in Ireland. At pp. 620-621 he observed:-

> "I do not think that it lies within the prerogative of any parent or of this court to look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance. The matter was well put in an American decision - *Re Weberlist* (1974), 360 N.Y.S. 2d 783, at p. 787, where Justice Asch said: 'There is a strident cry in America to terminate the lives of other people - deemed physically or mentally defective ... Assuredly, one test of a civilisation is its concern with the survival of the "unfittest," a reversal of Darwin's formulation. . . . In this case, the court must decide what its ward would choose, if he were in a position to make a sound judgment.'

This last sentence puts it right. It is not appropriate for an external decision maker to apply his standards of what constitutes a liveable life and exercise the right to impose death if that standard is not met in his estimation […]'"

154. The best interest test is to vindicate the ward's right to life as he would exercise it, not as the court would view it. The subjective character of the test is in acknowledgement of the fact that said right is the ward's right, which they may exercise in whatever way they deem fit. Abstaining from life-saving or life-sustaining treatment is only viewed as lawful vindication of a ward's right to life where the court is satisfied that the ward would choose such a course of action to be in his or her best interest.

155. In practical terms, this has the following effects. First, to establish what the ward would do, the court consults with those closest to the ward, family and treating doctors as well as any additional witnesses that the parties may wish to call. Having heard their evidence, it is then for this court to determine what the ward would view as being in their best interests in light of it. It is important to emphasise, however, that the subjective character of the test does not mean

that the court cannot assess, for example, the medical evidence soberly and realistically. The court, in the same way the ward would, must squarely face the facts, however unpleasant that may be. But, in carrying out its assessment of what is in the ward's best interests the court must have regard to the peculiarities and characteristics of the ward and how they would view it were they in a position to carry out such an assessment.

156. However, any such assessment must not be carried out lightly. As was set out by Lynch J. in *In re a Ward of Court* at 98:-

> "[...] I am well aware of the difficulties involved in applying this test. As was pointed out in argument and also in many of the cases cited to me, a patient in the whole of his health and in the full flush of youth, may have expressed robust views about not being maintained in an incapacitated condition but when actually in such a condition, might be very anxious to cling onto such life with such limited pleasures that still might remain to him [...]"

157. Furthermore, in establishing a ward's wishes, his or her parents are likely to give evidence as to what they believe to be in the best interests of the ward and what they believe the ward would choose. Although any such evidence is no doubt material to any application, the court must be weary that this evidence may be coloured by emotion as well as their own desire to keep their child in their lives. They may also be blinded by their love for them to recognise the full extent of the situation their child finds themselves in.

158. Lastly, as the precise considerations which fall to be considered and the weight attached to them are determined by reference to how the ward, in this case John, would make the decision, it is difficult to look at past cases and give a set list of factors which the court must take into account when deciding what would be in his best interests. Nevertheless, because there is a degree of similarity between cases and because there is always some difficulty in ascertaining the ward's wishes, it may be useful to mention what kind of factors have been

taken into account by the courts in the past when deciding upon applications of this kind. In *In re a Ward of Court* Denham J. gave perhaps the most extensive and detailed non-exhaustive list. She listed the following factors as relevant, while also stating that the totality of the ward's position must be taken into account:-

"(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 a 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."

159. Having assessed in some detail the objective behind the wardship jurisdiction as well as the nature and purpose of the best interest test, it should be clear why the wardship jurisdiction is the appropriate forum for this dispute and that, contrary to the submissions made on John's mother's behalf, the existing case law must apply to the present proceedings. First, regarding the best interest test itself, it is evident from what I have already stated that there are strong safeguards implicit in its formulation, the effectiveness of which are not diminished by the fact that the application is brought very early in John's post-accident life. The strong presumption in favour of life, the subjective nature of the test, the care taken when determining John's wishes and the checks and balances of the consultative wardship procedure apply with equal force to John's application as they do to any other application. None of these protective measures become less effective in the circumstances of this case. Therefore, John's right to life is adequately vindicated by the application of the best interest test.

160. As for the contention that the test inadequately protects the parents' constitutional rights, it is important to note that, once the hurdles of Articles 41 and 42A have been overcome, the parents' rights take a backseat. This application is determined by reference to how John would make the decision. The court applies the subjective best interests test and not, as is common in wardship matters, the prudent and loving parent test for a reason. Here, the court

is, above all, concerned with how John's right to life is best vindicated. This does not mean that the views of the parents are not material in determining what John would choose, but their rights as parents are secondary to John's interests.

Clear and Convincing Evidence

161. When applying the best interests test, the court must be convinced that there is clear and convincing evidence regarding the best interests of the ward to enable it to make a decision in the case. The standard of proof was set out quite clearly by Kelly P. in *J.M.* at paras. 94-96:-

> "There was a divergence of opinion amongst judges on this topic [the standard of proof] 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'.
>
> 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.'

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."

162. Ms. Phelan submitted that, in light of the new evidence, there is now greater uncertainty as to John's condition and prognosis and that, consequently, it cannot be said that there is clear and convincing evidence as to what would be in John's best interests. Besides the updated medical reports, she points towards statements made by Dr W. that John is "comfortable" that there is "no active suffering" and no "moral distress". She also refers to the supplemental testimony given by Prof. D. that John is a different patient. Ms. Phelan also argued that the new evidence suggests that, following a first stint in ICU, John may have extended periods of dystonia-free living in circumstances where his dystonia has been brought under control before. In light of that eventuality, it cannot be said that there is clear and cogent evidence as to John's prognosis and what is or is not in his best interests.

163. The new evidence shows that the symptoms of John's dystonia have ceased. It also shows that the objective markers for pain, i.e. an elevated heart rate and sweating, have subsided. Therefore, I accept that John does not currently suffer from dystonic episodes which means that he is, in all likelihood, pain free at this time. Although this evidence undoubtedly establishes that John's present condition has changed, it has not altered his long-term outlook or the effect ICU treatment will have upon him. His body will decondition, his health trajectory will diminish with admission to ICU and with each subsequent admission. His dystonia is very likely to become de-regulated when admitted to ICU and it is just as uncertain as it has been prior to the new evidence being adduced that his doctors will be in a position to re-establish the equilibrium of medication that gives John the window of peace he currently enjoys.

164. Furthermore, the new evidence does not alter the fact that John will not recover significantly from his injuries. His neurological condition remains unchanged and his outlook is as bleak as it was when the court first heard evidence on the present application. ICU will not provide John with a bridge to recovery, which is what invasive measures are designed to achieve. Nothing in the new evidence changes that. ICU will however be a source of great distress to John and will catapult him into the cycle of pain, loss of dystonic control followed by a recovery to a lesser health trajectory than he enjoyed before the crisis, only so that the whole process can repeat until he finally succumbs.

165. In addition, the need for the subcutaneous infusion has not been changed by the supplemental evidence. Although it seems that the new evidence indicates that a dystonic crisis is, for the time being, a more remote possibility and that, as a result, the need for a subcutaneous infusion has become less likely, should a dystonic crisis present itself, the evidence remains that John will need it just the same to bring his pain under control. Dr G. was explicit about this.

166. Thus, it cannot be said that the evidence is not clear and convincing. A change in the evidence regarding John's present-day condition casts no material doubt upon whether or not, from a medical point of view, the withholding of ICU treatment or the administration of pain medication is in his best interests.

Clinical Judgment

167. This brings me to mention briefly a point canvassed on behalf of John's father by Mr. Colin Smith, B.L., who suggested to several of John's treating clinicians that if they considered the invasive measures would not be in his best interests that they did not require any court order to withhold them. I inferred from this line of questioning that I was being asked to consider the possibility that because the clinicians said they would instigate invasive measures if a crisis was to occur in the near future, that they were somehow unsure that such an approach was not in John's best interests.

168. It seems to me however that this does not indicate anything of that kind. The doctors are unanimous and consistent in what they believe to be in John's best interests. However, the problem for them is that their patient has not specifically authorised any particular approach to his treatment. As a result, the clinicians cannot be sure what treatment they should administer if John's condition deteriorates. The uncertainty exists because John cannot say in which direction his care should now go, not because the clinicians are unsure as to the benefit of the approach they propose.

169. Furthermore, John's parents remain staunchly opposed to any course of action which could shorten John's life if it can be prolonged by intervention. And, in light of those objections the clinicians do not believe they can simply follow their own clinical judgment and withhold treatment unless it is clear beyond doubt that the invasive measures would be futile. By futile I mean that the invasive measures would stand no chance of success. Given that the clinicians

believe that John would probably survive a crisis if it was to happen in the near future and knowing of the wishes of John's parents and of the fact that his life might be saved, they could not fail to intervene.

170. Moreover, John's treating clinicians entered into an agreement with his parents that until such time as they could bring an application such as this to the court, that they would take all steps to prolong John's life even if it meant intervening with invasive measures which they did not consider to be in his best interests. Whilst perhaps of lesser importance the court also heard how John's doctors feared that if they followed their own clinical judgment and failed to intervene to save John's life, they might be exposing the hospital to future litigation. In these circumstances I am satisfied that without a court order John's clinician will not be in a position to act in his best interests.

What Would John Want?

171. The fact that the patient under consideration is of tender years might in another case be a reason for not attaching substantial weight to what the court considers that child might consider to be in his or her best interests. However, I do not believe that to be so in the present case for a number of reasons.

172. First, there is nothing to suggest that John's experience of pain and his ability to tolerate pain should be much different to that of an adult faced with similar pain. So, once the type and extent of the pain to which John will be subjected, depending upon the approach taken to his future care, is relatively clear it should not be too difficult to assess what John would want if faced with either the prospect of invasive measures in ICU or dystonia which can only be relieved satisfactorily by the use of subcutaneous infusion.

173. Second, insofar as the court might attach weight to the view it considers John would have concerning the life ahead of him in the event of invasive measures being instigated, he

has lived enough of life to know the difference between the life he would have had if this terrible accident had not happened and the life that he will face if he is to receive invasive measures in the event of a crisis. His position is not akin to that of an eleven-year-old child brain-damaged and quadriplegic from birth who could have no expectation of enjoying a life such as that which John, because of his lived experience would expect to enjoy.

174. Accordingly, bearing in mind the presumption in favour of delivering life-sustaining treatment and the factors and evidence earlier referred to, I will now consider what I believe John would want if he could voice his opinion on the following two questions. First, if his health was to decline to the point that his life could only be saved by being taken to the ICU where invasive measures would be instigated, would he want his clinicians to intervene knowing the damage they would cause and the increase in pain they would probably cause? Or, would he more likely elect to reject those interventions in favour of treatment that would keep him comfortable and pain-free for as long as possible? Second, in the event of his dystonia becoming symptomatic to the point that it could only be controlled by subcutaneous infusion, would he ask to be given that treatment knowing that it might lead to respiratory compromise and the foreshortening of his life or would he decline that treatment in favour of less effective pain control?

175. For the purpose of answering these questions, I must have regard to all of what I have been told about John in terms of his character, his interests and his life. I must approach my decision remembering that, although his parents are separated, John comes from a tightknit family and that he is particularly close to his mother and his second eldest brother. I must focus upon how he loved school and has good friends. And, I must think about John as a relatively carefree young man who is an ardent Liverpool supporter, a keen follower of American wrestling and who loves music, in particular that of Nathan Carter.

176. I must also have regard to what I have been told by his parents as to what they believe John would want, both in terms of his present care and his care in the event of a crisis. They believe he would want to fight on regardless of the difficulties facing him because, according to his mother, he has the "heart of a lion".

177. In deciding what John would want I have tried to put myself into his young head and heart. I have reflected on all of his interests and what I know of his experience of life to date, both within and beyond his family. Although still relatively young, I have thought about what John might consider to be a worthwhile and meaningful life. And, from observing the lives of his parents, and those of his older sister and brothers I must assume that he expected that he would enjoy a life full of opportunity, subject of course to life's occasional disappointments and upsets. I'm sure John expected he would get a good education and later employment that would give him the chance to pursue his many interests and that he would derive great enjoyment from the comfort of family and friends. In the course of the evidence I heard that John has expressed an interest in becoming a vet. And, having regard to what young people such as John are currently exposed to on television and social media, I would be highly surprised if, before his accident, John was not already thinking that at some stage in his life he would fall in love and find a partner with whom he would share his life and perhaps have his own family.

178. In making my decision I have also proceeded on the basis that John's love for his family, and in particular his love for his mother, is as strong as any relationship can be between a mother and son. I have taken this approach not only because of what I have heard in evidence in recent weeks but also because I have had the benefit of seeing the really close bond that exists between John's mother and his eldest brother who has been by her side to support and comfort her throughout this case. Anyone observing that relationship would recognise the depth of feeling and love they share. This, combined with what has been described as John's mother's

immaculate care of him throughout his hospitalisation satisfies me that this is the correct approach. Accordingly, I have assumed that John would probably accept more pain than almost any other child if by doing so he could prolong his relationship with his parents and siblings.

179. Having said all of that, I must ground my decision in the real world and what I have heard of John's condition and his pain. And, I must give John the voice that he presently does not have to make known what he would want to happen in terms of management of the types of crises discussed in evidence. I regret that in giving my reasons I must speak using very direct and plain language because this judgment has monumental consequences for John's parents.

180. It is all too easy for someone like me who is not in pain to intellectualise pain. All I can say is that I truly believe that most of us have very little capacity to tolerate pain, particularly if it is pain which, when it occurs, would be described by clinicians who see a lot of pain, as "cruel". And, being human, if our pain is in someone else's control we invariably expect that those in charge of our medical care will to do everything possible to subdue it**.**

181. I also recognise that there are many people who are strong enough to willingly put themselves through painful medical treatment or intervention. However, in my experience that usually only happens where the treatment or intervention offers the patient the possibility of a cure or an improvement in their condition and where they believe that the treatment will restore their health to a position where they can at least look forward to some enjoyment of life. The patient will likely weigh up the level and duration of the pain to be endured and balance that against the benefit that accepting that pain will probably bring.

182. But what is proposed here is treatment which is not to be undertaken with a view to improving John's condition or affording him even the remotest possibility of any enjoyment of life. The objective of instigating invasive measures would solely be to artificially extend John's life, regardless of the consequences of those measures. Assuming John survives such aggressive intervention, the evidence is clear that he will be left in a physically worse state of

health than he was in before his crisis, allied to which he will suffer a significant if presently unquantifiable amount of additional uncontrolled pain and all so that he can remain in a semi-vegetative or minimally conscious state until that cycle of crisis followed by intervention followed by more pain, repeats itself at increasingly shorter intervals until such time as his frail body can take it no longer. And it is this knowledge that I must impute to John when I come to consider how he would answer the questions earlier mentioned.

183. In the course of my own relatively long life, I have met many people who have shown great strength and resilience in the face of adversity but I know none that if in John's shoes would choose treatment designed to prolong their life and escalate their pain rather than treatment that would make them comfortable for the rest of their life particularly in circumstances where the pain to be endured would reap nothing in terms of future happiness or joy.

184. I do not believe it credible or even remotely possible that John, knowing that he will spend most of the rest of his life in a hospital bed and will never walk, never talk, never see, never go to school, never have new friends, never communicate, never feel love, happiness or pleasure, will be doubly incontinent and will if he survives invasive measures, endure significant periods of pain, would, if faced with a crisis of the type anticipated, instead of saying "do everything you can to make sure I suffer as little pain as possible" say "I would prefer you to take me to the ICU and do whatever is necessary to keep me alive" knowing that if he needed CPR, the measures taken would likely involve breaking his ribs and inflicting other damage only to return him to a health trajectory worse than that which he faced before his crisis. I am equally certain that, faced with a level of pain that could not be controlled other than by use of a subcutaneous infusion, John would want to receive that treatment even if it might lead to respiratory compromise.

185. I say all this because I have no reason to believe that John, if he had a voice, would not respond in the same way as the children and adults suffering from dystonia who have been spoken about by the clinicians in the course of their evidence. And, as we know, John's case is very different from almost all others insofar as his dystonia for many weeks was at the severest end of the spectrum and it is likely that following invasive measures he will experience significant periods of very severe pain at a minimum for several weeks, if not longer.

186. All I can say to John's parents is that I truly believe that if John could speak knowing what was facing him in ICU and in terms of his life thereafter he would plead with them to save him from the trauma and pain ahead when this present window of calm ends, as is an absolute certainty. I know John would not willingly consent to that treatment. He would want the alternative approach to be taken, namely that he would be kept as comfortable and safe as possible for as long as possible in the arms and care of those best equipped to mind him. And I believe that when faced with dystonic pain that was out of control he would want his parents and doctors to give him the most effective treatment available to treat that pain even if it might shorten his life.

187. For these reasons I have no doubt that it is in John's best interests and in accordance with what he would wish that he should not be subjected to invasive measures of the type set out at para. 4 (ix) of the Notice of Motion unless his clinicians consider that any one or more of them are in John's best interests and that his clinicians should be entitled to manage his care in accordance with the terms of the permissive orders sought at para. 4 (i)-(xiii) of the Notice of Motion.

188. It would be grossly remiss of me to end this judgment without stating that I am full of admiration for John's parents. They have been a constant presence at his bedside since his accident, and the clinicians in charge of his care have roundly praised the support and love they have shown for John throughout the harrowing period. It may be that the depth of their love

for John and the chasm that his premature death will bring to their lives, combined with the fact that John cannot tell them of the enormity of his pain, that they hold fast to the idea that his pain is somehow tolerable in the face of a tsunami of evidence to the contrary given by clinicians who between them have decades of experience of dystonia.

189. In making my orders today, I truly believe that not only will John be the beneficiary of the plan now proposed by the hospital, but that his parents will, within a relatively short period of time, come to see the benefit of that plan for the whole family. I say this because for the first time there is at least a prospect that John may be able to be discharged to a regional hospital closer to his home or to a unit where his comfort and the support of his family will be the goal of his carers, whereas, in the absence of such orders John would appear destined to spend the rest of his life enduring great pain in a specialist hospital only so that his life could be extended by invasive measures in the event of a crisis. I hope John's parents will, in time, come to accept that this is what John would choose.