

Neutral Citation Number: [2013] EWHC 2340 (Fam)
IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

19 September 2013

Before :

THE HONOURABLE MR JUSTICE PETER JACKSON

Between :

AN NHS FOUNDATION TRUST

Applicant

-and-

R (Child)

1st Respondent

-and-

Mr and Mrs R (Parents)

2nd & 3rd
Respondents

Joseph O'Brien (instructed by Hempsons Solicitors) for the Trust
Vikram Sachdeva (instructed by Irwin Mitchell LLP) for the Parents
Claire Watson (instructed by CAFCASS) for the Child

Hearing dates: 29 to 31 July 2013
Date of decision: 31 July 2013
Date of final judgment: 13 December 2013

JUDGMENT

Mr Justice Peter Jackson:

Explanation

The judgment that follows was sent to the parties in August 2013 after a hearing in July. A hearing was fixed for September for the public hand-down of judgment and for final orders to be made. However, shortly before that hearing, Reyhan's parents applied for further evidence to be admitted. Their application was heard on 18 October and directions were given for the new evidence to be considered a further hearing on 31 October. Sadly, Reyhan died on 23 October. The judgment is now published with the consent of the parties.

Judgment

1. These proceedings arise from a disagreement about what is in the best interests of Reyhan, who was born on 2 June 2012 and is now 14 months old. He has profound developmental delay and has never left hospital. He cannot breathe for himself and requires continuous artificial ventilation. His condition is progressive and ultimately fatal. If ventilation is continued, his life expectancy is reduced but uncertain; if it is withdrawn he will rapidly die.
2. The parents, along with Reyhan's whole family, want him to move to live at home with a package of care including long-term ventilation. The treating doctors consider that this would be too burdensome for Reyhan and that it would be in his best interests for ventilation to be withdrawn, allowing him to die in comfort. On 21 March 2013, the Trust responsible for the hospital where Reyhan is being treated began these proceedings.
3. In the course of a hearing in public that lasted three days, evidence was given by the parents and four other family members, by three treating doctors, by an expert called by the parents and by the Children's Guardian. On 31 July, at the end of the hearing, I informed the parties of my conclusion that continued ventilation was not in Reyhan's best interests. I gave my reasons and adjourned to give the family the opportunity to absorb the decision and to allow the parties to consider what arrangements should be made. Interim orders were agreed, providing for a reduction in the treatment response if Reyhan's condition were to deteriorate in the meantime. At the resumed hearing in September, final orders will be made.
4. The only restriction on publishing information in this case is that the family surname is to be withheld, together with the identities of the Trust, the hospital and the treating staff. This is to allow the family to have privacy at a sad and difficult time. There is no intention to inhibit discussion of the issues that arise.

Narrative

5. Reyhan is by some distance the youngest of his parents' six children, the older five being between 27 and 14 years old. The family is extremely close, with most members living in or near to the family home. Reyhan was a much-wanted child and his father describes the occasion of his birth as a joyous day. Reyhan was soon found not to be sucking and he was diagnosed with Down's Syndrome. This did not discourage the family, who are by character and religious conviction completely committed to looking after their own.
6. Unfortunately, matters did not improve. Reyhan experienced breathing difficulties and on 18 July 2012 he was transferred to the specialist hospital where he is currently being treated. On 24 August 2012, he was moved to the Paediatric Intensive Care Unit (PICU), where he has remained ever since.
7. Extensive diagnostic tests carried out between July and October 2012 established that Reyhan has the following diagnosis:
 - (a) Down's Syndrome (genetically confirmed trisomy 21);
 - (b) Mitochondrial myopathy (respiratory chain complex I and IV deficiencies in skeleton muscle biopsy, genetic basis not established).
8. Mitochondrial disease is a group of disorders caused by faulty mitochondria within human cells. Mitochondria convert the energy contained in food molecules into energy that can be used by the body and particularly by the muscles. The condition affects Reyhan in the following ways:
 - (a) He suffers profound neurological problems and has not met any of his infant developmental milestones. As a result of brain impairment and muscular weakness, he has no gag reflex (a most basic function) and no deep reflexes in the major joints. He has a normal sleep/wake pattern.
 - (b) He has severe and progressive muscle weakness. He cannot lift his body or limbs against gravity. He makes some shifting movements of his hands and feet and can turn his head a little from side to side. He can open his eyes slightly and has uncontrolled, disconjugate, roving eye movements.
 - (c) He is unable to take deep breaths or cough as a result of the weakness of his diaphragm. He was initially given intermittent, non-invasive CPAP (continuous positive airway pressure), which provides a constant low level air pressure to the airway to assist natural breathing. However, worsening respiratory failure led to the use of SiPAP (synchronised intermittent positive airway pressure) and at times since September 2012 and continuously since January 2013 he has needed BiPAP (bi-phasic positive airway pressure) where a set number of breaths are supported by the mechanical ventilator.
 - (d) Secretions are prone to build up in Reyhan's lungs, which act as a focus for infection. He needs to have his airways suctioned on a regular basis to keep them clear. Shallow suctioning is performed regularly and appears to

be tolerated; deep suctioning is performed occasionally as necessary and appears to be distressing. Reyhan has chest physiotherapy in an attempt to keep his airways clear; this too requires him to undergo suctioning. A tracheotomy was performed on 30 October to facilitate ongoing care, but this artificial airway is also a portal for infective organisms to enter the body and as a result, Reyhan is susceptible to chest infections and pneumonia.

- (e) He is unable to swallow and cannot eat or drink for himself. He is fed by a pump which passes feeds into a tube in his stomach for 18 hours of the day.
 - (f) He cannot communicate in any way, apart from squirming and grimacing in response to noxious stimulation.
 - (g) He responds to bright light, but is unable to fix and follow.
 - (h) He has a moderate to severe neural hearing defect, but he will react to loud or sudden sounds.
 - (i) He has seizures, which are currently well-controlled by anticonvulsant medication.
9. The contribution of Reyhan's family has rightly been described as matchless by all the medical staff. Family members are a constant presence. One or other parent is always with him during the daytime and other family members visit in numbers on a daily basis, despite the journey that is involved. The parents in particular are skilled in meeting his care needs – for example they have been trained to perform shallow suctioning – and are well-informed about his medical condition. The family members do everything they can to stimulate Reyhan and help him to reach his potential.
10. If continuously ventilated and rescued from intercurrent infections, Reyhan's life expectancy is uncertain but is reduced to some years at most. Although no doctor could give a prediction, the overall effect of the evidence left me with the impression that he is at best unlikely to reach his second decade. In August 2012, he was severely ill, but recovered. In January 2013, he again suffered a serious infection and in July 2013, he had an episode of cellulitis infection affecting his left arm. Apart from this, his condition is currently stable: i.e. at the time of the hearing and for several months beforehand, he had not been deteriorating rapidly, but slowly in accordance with his underlying condition.
11. There is relatively little disagreement about Reyhan's condition and his prognosis. The issue is whether it is in his best interests for mechanical ventilation to be withdrawn.
12. Reyhan has, in the view of the treating doctors, a minimal level of awareness of his surroundings. They accept that he seems to respond to the family's

excellent care and skilled handling: he is seen to react to being in his parents' arms by a drop in his heart rate consistent with a feeling of comfort. However, it is the unanimous view of the treating clinicians that it is not in his best interests to continue living by means of long-term ventilation. They consider that such treatment is delaying his death without significantly alleviating his suffering and have concluded that his condition falls into the "No Chance" category of the Royal College of Paediatrics and Child Health guidance "Withholding or Withdrawing of Life Sustaining Treatment in Children: A Framework for Practice" (2nd edition, 2004):

"Treatment delays death but neither improves life's quality nor potential. Needlessly prolonging treatment in these circumstances is futile and burdensome and not in the best interests of the patient; ..."

13. With the agreement of Reyhan's family, a second opinion was obtained in November 2012 from Dr Rahman, Reader and Consultant in Paediatric Metabolic Medicine at Great Ormond Street Hospital. She examined him and confirmed the diagnosis. She advised on further tests, some of which were carried out, while the family preferred not to pursue others. Dr Rahman states that in view of Reyhan's clinical deterioration and the exclusion of any known cause for his mitochondrial myopathy, it is now extremely unlikely that he will recover and that it is not in his best interests to continue on long term ventilation.
14. The parents do not consent to the withdrawal of treatment, due to their firmly held belief that Reyhan shares a loving bond with his family and has a quality of life that enables him to interact. They perceive that he experiences pleasure during their interactions with him and that this is indicated by a small smile, moving his eyes towards the sound of their voices, hand movements and increased activity. Moreover, as practising Muslims they hold conscientious beliefs about the sanctity of life and the duty of the family.
15. In practical terms, there are three options. The first is the continuation of maximum treatment, as has been taking place so far, with aggressive countermeasures to acute deterioration, such as delivery of intravenous antibiotics by central line. This is agreed to be inappropriate, and the central line, which recently became dislodged, is no longer in place and will not be reinstated. The second option is continued ventilation with limited surrounding treatment underpinned by an agreement that treatment would not be escalated in the event of deterioration. Under this arrangement, after a period of planning and preparation necessarily lasting some nine months, Reyhan would move home and be cared for by the family and a substantial local care team. The third option is the withdrawal of ventilation, with accompanying sedation so that Reyhan would suffer a pain-free death. This could occur in hospital or at home, at the family's choice.
16. As described above, the family seeks an outcome in accordance with the second option. The treating doctors favour the third option. Although they do

not consider the second option to be in Reyhan's best interests, they would nonetheless, with considerable misgivings, be prepared to give effect to a contrary declaration by the court. They would not be prepared to treat Reyhan in accordance with the first option.

17. As would be expected, a number of meetings were held in an attempt to find a joint way forward, both before and after proceedings were issued. Furthermore, in December and January, in deference to the view of the family and despite the unchanged views of the doctors about Reyhan's best interests, the Trust took steps to progress Reyhan's return home under a non-escalation agreement. That plan was abandoned in February as a result of deterioration in Reyhan's health and because of unhappiness on the part of the family with the prospect of non-escalation of treatment.

A summary of the evidence

18. On behalf of the Trust, evidence was given by Dr A, Consultant Paediatric Neurologist, Dr B, Consultant Paediatric Intensivist and Reyhan's lead clinician until March 2013, and Dr C, Consultant Paediatric Intensivist and lead clinician since March 2013.
19. Dr A confirmed that Reyhan could be seen to grimace, denoting pain or discomfort, and noted that if he experiences pleasure, one should equally be able to see a smile, but she has never seen this. She interpreted the family's reports of a subtle smile as reflecting their natural hopes and expectations. She had wrestled with the dilemma of future treatment ever since Reyhan was admitted to the PICU, and had concluded that further ventilation was not appropriate. His disorder is severe, incurable and terminal, and will lead in natural course to progressive weakness, chest infection, respiratory failure and death. This natural process is not being allowed to happen. Provision of long-term ventilation in the community to a child with a progressive, incurable condition would be unique in her experience.
20. Dr A spoke of the wider human and ethical considerations, and readily accepted that the best interests of the family can be relevant provided the interests of the child are engaged. Although many severely disabled children consider their quality of life to be very good, in Reyhan's case she could find no benefit to him other than life itself. It is impossible to be certain about what he is feeling, and he cannot communicate or react to sensations himself, such as by scratching an itch. His existence is already one of total dependence, and his condition will inexorably deteriorate. In Dr A's opinion, he should be allowed to die in peace with his family.
21. Dr B is of the view that Reyhan's disease is gradually but relentlessly progressing and that he is suffering, for example as a result of deep suctioning. Desaturations of oxygen as a result of blocked airways will be very uncomfortable. He is concerned that we cannot predict how and when Reyhan will be suffering and that he cannot let people know how bad his pain is. Nor

can we tell whether he finds well-intentioned efforts to stimulate him pleasurable or unpleasant. Mechanical ventilation should be discontinued under the cover of intravenous infusion of opiates and sedative drugs that would guarantee that he dies in comfort.

22. Dr C, the current lead consultant, referred to the burdens of intensive care, for example suctioning, and observes that where a child has a good quality of life, the benefits of providing long term ventilation outweigh the burdensome nature of suctioning and routine ventilatory supportive care. However, in Reyhan's case, while these procedures are not currently overwhelmingly burdensome, long term ventilation provides no apparent benefit to him except to keep him alive with no prospect of an improvement in his condition and in circumstances where he is not able to appreciate or respond to his environment. Dr C does not consider it right to insist on enforcing this form of treatment where there is no good evidence that Reyhan experiences any form of pleasure beyond settling back from discomfort. He underlined the very painful nature of deep suctioning according to child survivors of the procedure. He emphasises that we can be sure that Reyhan will not get better and that for a child with such profound dependence on ventilation, the unpleasant burdens of the condition increase with age. There is a risk of painful pathological fractures caused by osteoporosis and failure of the bones to mature. Poor musculature around the spine invariably leads over time to kyphoscoliosis requiring splints, chest braces and seating. Many children who are immobile to the extent of Reyhan will also develop kidney stones leading to urinary infections and abdominal spasms. Dr C supports the Trust's application to withdraw treatment from Reyhan on the basis that his current treatment serves no purpose in view of the extreme limitation his condition imposes on him. The benefit of life must be given considerable weight, but here it is outweighed by the burdens of continuing to provide care.
23. Opinions underpinning and supporting those of the above witnesses have been obtained from other treating clinicians: Dr D, a Consultant in Paediatric Respiratory Medicine, and Dr E, a Consultant Paediatrician with a special interest in Metabolic Diseases.
24. The only difference of any significance between the three treating clinicians who gave oral evidence concerned the practicality of a "non-escalation agreement". Dr A and Dr B felt that in the light of experience, it would be asking too much of the family to stick to such an agreement if Reyhan became severely ill at home, while Dr C was more optimistic than it could be made to work.
25. Evidence was given by the father and mother, by Reyhan's eldest brother, by two of the mother's brothers, and by one of their wives. They presented a strong, united position.
26. The father said that they want Reyhan to come home. They would not insist on increased treatment in the event of deterioration as they would not want

Reyhan to suffer or struggle. They know his condition is progressive and they will know when he has had enough. They think that he is not in pain, that he currently gets pleasure from life, and that he interacts and is aware of his surroundings. For example, he knows when his father or mother are there and will let you know if he does not like something. They see him as happy most of the time. They will not be able to know his full potential until they are able to take him home. Through research, they have learned of another child with mitochondrial disorder who lives at home with a package of ventilation and associated care.

27. The family has made a series of film clips of Reyhan, which the father described as they were being played in court, and which give a good idea of Reyhan's situation and of the family's passionate belief in his value and potential.
28. The mother spoke of knowing Reyhan better than anyone. She felt that he had been in pain in the past, but this was no longer so. He was able to feel pain and comfort and to show some preferences. If Reyhan was suffering, she would let him go, though it would break her heart. At the end of her evidence, the mother was overcome and had to be helped from court, epitomising how stressful the situation is for the whole family.
29. One of the mother's brothers spoke of how he could detect very subtle reactions in Reyhan, and said that he is confident that he feels and senses. It has been a long year, but to take his short life from him would be something the family would never get over.
30. Another of the brothers saw Reyhan as starting to enjoy life and described how leaving hospital would let Reyhan have new experiences – hearing a dog bark or seeing a bird. His wife confirmed that the family is trying to expand Reyhan's quality of life by helping him use his senses. He is making new movements and showing new reactions. Having him at home would allow him to be given much more, to improve his existence and to build joyful memories.
31. Reyhan's eldest brother described him as a fantastic addition to the family. Sacrifices had been made, and the family had become the stronger for it. There have been really bad times, but now he has a quality of life and a two-way bond with his family. Reyhan will die when it is God's will that he should, and it would be a devastation for the family if the moment were advanced by the court's decision.
32. Each of the family members spoke from the heart. Their devotion to Reyhan is outstanding.
33. The other medical witness was Professor Michael Vloeberghs, Consultant Neurosurgeon at Nottingham University Hospital, who was instructed by the parents. He has examined Reyhan twice and is in agreement with the

diagnosis and prognosis of his medical colleagues. There are no other tests that should be carried out.

34. In Professor Vloeberghs' opinion, Reyhan's condition is irreversible and will lead to his death. From a purely objective point of view, ventilation would be futile: it will not cure him or in a strict sense palliate his illness. However, Professor Vloeberghs does not advocate withdrawal of ventilation:

"... I find it very difficult to dissociate the wellbeing of the child from the wellbeing of the family. The family need to live on within their own social framework and beliefs and need to feel comfortable with every decision made. If the child's family are uncomfortable with any decision made by a third party this may have devastating effects on the family dynamics and future relations."

He also draws attention to the acute difficulties in withdrawing life support without the participation of the family.

35. Professor Vloeberghs said that he is inclined in some respects to credit the family's observations of some level of interactive behaviour by Reyhan. For example, he observed him appear to move his hand as if to touch a button on a toy laptop that then played music. He considers Reyhan to have a degree of awareness and to be capable of a feeling of well-being – he is 'still there'. Ventilation should not be withdrawn now, and the situation should be reassessed when he deteriorates.
36. Professor Vloeberghs spoke of his responsibilities for a large contingent of severely disabled children with a wide range of movement disorders arising from a variety of causes, saying that many of these are sustained by long term ventilation in the community. However, on further inquiry it became clear that none has a severe progressive illness of the kind suffered by Reyhan.
37. The final witness was the Children's Guardian, Mr John Mellor. He observes that Reyhan's survival in his relatively stable current state is due to his being so well cared for by the clinical and nursing team and his devoted parents. He notes that Reyhan is profoundly and globally developmentally delayed, is totally reliant on others to carry out his personal care, and will be for the remainder of his life. If he were to survive beyond infancy there is a long list of potential complications, interventions and further operations that he will experience. It is most unlikely that Reyhan is truly aware of the benefits of continuing with long term ventilation that is keeping him alive. Having weighed all the information available, Mr Mellor concludes that it is in Reyhan's best interests for his ventilation to be withdrawn in a planned way to allow him to die peacefully and with dignity.
38. Giving evidence, Mr Mellor described the family as being in a state of ongoing trauma, akin to bereavement, and as having responded with remarkable unanimity in its deep love and closeness to Reyhan. When he saw

Reyhan himself, he did not observe the reactions the family senses, nor did he see them in the films where the family say they can be seen. It is extremely sad to have to face the reality of death so early in a life, but Reyhan is entitled to a good death.

39. Mr Mellor described this as a particularly difficult decision, and said there is something about what has happened between the family and hospital, perhaps arising from the previous discussion of a return home, which had led to the present situation, which he described as a terrible, terrible shame.

Legal principles

40. In the quarter of a century since the decision in Re J (Wardship : Medical Treatment) [1991] Fam. 33, situations of the present kind have arisen with some regularity and the principles to be applied are clear. The court must, taking account of all relevant matters and treating the child's welfare in the widest sense as its paramount consideration, decide what is in the child's best interests, looking at it from the child's point of view and applying a strong, though rebuttable, presumption in favour of a course of action that would prolong life: Wyatt v Portsmouth Hospital NHS Trust [2005] EWCA Civ 1181.
41. I have also been referred to and been assisted by the judgments of Holman J in NHS Trust v MB [2006] EWHC 507 (Fam), of Parker J in Re OT [2009] EWHC 633 (Fam), of Hedley J in NHS Trust v Baby X 127 BMLR 188, and of Baker J in Re M [2012] 1 WLR 1653.
42. Even so, there is always more to be learned in a field where profound questions must be answered and, as this judgment is being prepared, the decision of the Supreme Court in the appeal in Aintree University Hospital NHS Foundation Trust v J [2013] EWCA Civ 65 concerning the concept of futility of treatment is awaited. However, it would not in my view be right for the decision about Reyhan to have been delayed to await the outcome in that case, bearing in mind in particular the family's need for a resolution.¹

Discussion and conclusion

43. In assessing Reyhan's best interests, assisted by a Guardian of the greatest experience, I do not limit my consideration to his medical condition in isolation, but also weigh the emotional, social and existential factors that underpin his right to respect as a unique individual, a member of his family, and a member of society. These considerations are protected by Articles 2, 3

¹ This was the position on 31 July. The Supreme Court decision in the Aintree case, [2013] UKSC 67, was handed down on 30 October. Had a new approach to decisions of this kind been required, the hearing on 31 October would have been the occasion for this – but it did not, and the hearing did not of course take place.

and 8 of the European Convention on Human Rights and Fundamental Freedoms 1950.

44. A decision that ventilation should be withdrawn will be devastating to Reyhan's family, who have lost their hearts to him. They could not have done more. Their dignified participation in these distressing proceedings does them great credit.
45. I likewise pay tribute to the knowledge, professionalism and compassion of the treating doctors and nursing staff. Reyhan's currently stable condition is testimony to their skill, without which he would have died many times over. He has been their patient in the PICU for an exceptionally long time and they have thought deeply about what is best for him, while maintaining a respectful and supportive stance towards the family as a whole.
46. I accept the unanimous medical evidence that Reyhan is profoundly globally delayed by a condition that is inexorably progressive, incurable, and ultimately fatal. With maximum medical intervention, his life might be extended by an unknown number of years in further deteriorating health.
47. I find that Reyhan undoubtedly has a level of awareness. Despite his disability, he has some capacity to react to light and to sound. He experiences pain when he is intermittently unwell or when he has to be handled intrusively and he is responsive to human comfort. It is not possible to know what he makes of his life, but it is clear that he experiences it at a most basic level. His day-to-day condition is currently stable, although he had infections in January and July from which he recovered. All this is agreed. There is some disagreement, however, about his capacity to interact. In this regard, I prefer the evidence of the treating doctors to that of the family. There is, in my view, no dependable evidence that Reyhan has any meaningful ability to interact cognitively or purposefully with his environment. I note the views of the family, who believe that he has greater abilities, and indeed that these will increase over time, but I find that these are not objectively verifiable but are better understood as a projection of their hopes and ambitions for him. Reyhan inspires them, and their great love for him is reflected back. To the extent that Prof Vloeberghs endorses the family's views on this issue, I prefer the view of the clinical team.
48. I find that at the beginning of this year the Trust was prepared to offer a package of home care of the kind that the family now says that it is willing to accept. However, this was only proposed as a last-ditch attempt to achieve an agreed solution, and it was rejected by the family because it required them to agree to non-escalation of care in the event of deterioration. In the event the proposal was withdrawn following Reyhan's illness in late January. Significantly, the doctors have throughout maintained the view that long-term ventilation at home is not in his best interests. While this episode has complicated the relations between the family and the Trust, it does not form a central part of my assessment of the options currently available. In any case,

had the non-escalation agreement been put into effect months ago, it is by no means certain that Reyhan would be alive today.

49. I note that the clinical team (although it does not consider it in Reyhan's best interests) remains willing to offer a package of care at home if this is the court's decision, provided that there is a clear non-escalation agreement. In other words, they do not (and did not) regard such a course as being unethical. By the same token, I accept that in the great majority of cases of this kind, families will over time come to accept the medical advice, leading to the withdrawal of life-sustaining measures. Prof Vloeberghs said that if this had happened in Reyhan's case, it would have caused him no concern: it was the position of the family that gave him pause.
50. There is some difference of view as to whether a non-escalation agreement is practicable. Like the Guardian, I have real doubts about whether it is not asking too much of the family to abide by such an agreement, but I would not allow my doubts to stand in the way of an otherwise beneficial plan.
51. I accept the evidence of Prof Vloeberghs that very many profoundly disabled children live beneficially in the community with long-term ventilation. However, on inspection of his evidence it became clear that even he has no experience of this applying to any child with such profound degenerative disease as Reyhan. With regard to the family's information about another child with a similar condition who is being ventilated in the community, I am prepared to accept that if Reyhan was similarly treated, he would not be unique, but the facts of another case cannot be used as a guide to his best interests.
52. In balancing the many important factors in this case, I inevitably reflect first on Reyhan's most precious possession – his life. With continued ventilation, he may live for some years. A conclusion that it is in his best interests to be allowed to die can only be reached if it is clearly shown to be in his best interests. If there is doubt it must be resolved in favour of continued life. This reflects the unique value that society places on life itself.
53. Next, I take account of the deeply held views of the parents and wider family. The effect on them of Reyhan's death, when it comes, will be profound: if it comes earlier, and against their wishes, it will be even harder for them to bear. This consideration reflects Reyhan's place in his family, which has become central — at the moment, family life largely revolves around him. I accord great respect to these views, but in the end I must make my own evaluation.
54. I then consider Reyhan's level of awareness, the fact that he is currently medically stable and that he appears to experience sensations of comfort despite his predicament. This reflects the commitment and skill of his carers and family, and our remarkable ability to prolong life by scientific means.

55. Taken collectively, these are weighty considerations in favour of the outcome that the parents seek.
56. Chief among other considerations is the profound nature of Reyhan's disability and his extremely limited awareness. There is no question in this case of anyone undervaluing a person because he is disabled. His family could not be more proud of Reyhan. The doctors devote their professional lives to children with extremely severe disabilities such as this. It is important to assess Reyhan as an individual, taking a realistic view of what he can and cannot do, and seeking to look at it from his angle. While the depth of his disability means that we cannot know how intensely he experiences sensations, the evidence as a whole persuades me that his capacity for pleasurable feelings is very limited, amounting at best to some capacity to feel comforted. On the other hand, his capacity to feel discomfort or pain is much clearer, albeit that it is currently by no means a constant experience.
57. Reyhan's doctors are rightly concerned at the burdens of constant treatment. To the family, the paraphernalia of intensive care as seen in the films has become normal, almost invisible. But it is nonetheless clear that Reyhan can do nothing for himself. Everything is done for him and, to a degree that must cause concern, everything is done to him. Even now, he has very limited ability to communicate pain or discomfort – he cannot even cry out – and we know that suctioning of his airways undoubtedly involves a degree of discomfort extending at times to suffering. We cannot know whether he gains pleasure from well-meaning attempts to stimulate him or not. These considerations in themselves lead the doctors to recommend a withdrawal of ventilation on the basis of Reyhan's current condition.
58. Crucially, added to this, is the fact that from this very low base, Reyhan will continue to experience the gradual and relentless progress of his disease. He will not get better: he will get worse, and the treatments that he will require will become increasingly burdensome. His ability to tell us what that means for him will be further reduced, if indeed it does not disappear altogether. We will not know how much he suffers or if he is getting any pleasure. His death will have been delayed, but at what cost to Reyhan?
59. I agree with all the professional witnesses that this is an extremely difficult decision but, having considered the evidence as carefully as I can, I am not in doubt as to my conclusion.
60. I know that the family members believe that by surrounding Reyhan with infinite love and first-class care, they can protect him from many of the worst aspects of his condition, and I accept without question that they mean what they say. However, putting Reyhan first, I cannot in the end take the same view. The family members wish to continue on this journey, believing that they can carry Reyhan on their shoulders and put him down only when the time is right. This in my view overlooks the reality. If Reyhan is to continue on the journey of long-term ventilation, he will have to walk every step of the

way himself. Others can surround and encourage him, but it is Reyhan, and Reyhan alone, who will have to bear the burdens while experiencing little if any pleasure. And the road that he would be asked to walk is one that would grow steeper with every passing week.

61. Moreover, although the parents do not want Reyhan to suffer, my assessment is that the family's level of ambition and enthusiasm for his potential and for his survival is likely to lead to conflict and disagreement over what care should and should not be offered in a crisis. This could unintentionally expose Reyhan to suffering and may ultimately deprive him of dignity in death.
62. Having considered all these matters, I find that the treating doctors and the Children's Guardian are right in saying that it is in Reyhan's best interests for ventilation to be withdrawn. Continued long-term ventilation would be futile and would progressively cause him more and more suffering, while giving him very little in terms of any positive experience of the life that was being preserved by such intrusive medical intervention.
63. I regret the pain that this decision must cause, but hope that on further reflection the family will feel able to make arrangements with the doctors that will allow them to find peace for Reyhan, and some peace for themselves.
64. I will fix a further hearing in September at which the terms of the final order will be settled. In the meantime, I will make interim orders in the terms agreed concerning the extent of ongoing medical treatment and the protection of Reyhan's identity and that of the hospital and the medical staff. Time for appealing will run from the date of the final order.