



Neutral Citation Number: [2021] EWHC 1426 (Fam)

Case No: MA20P02742

**IN THE HIGH COURT OF JUSTICE**  
**FAMILY DIVISION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 28/05/2021

**Before:**

**THE HONOURABLE MR JUSTICE MACDONALD**

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**Between:**

**Manchester University NHS Foundation Trust**  
**- and -**

**Applicant**

**Alta Fixsler**  
**(By Her Children's Guardian)**  
**-and-**

**First Respondent**

**Mrs Fixsler**  
**-and-**

**Second Respondent**

**Mr Fixsler**

**Third Respondent**

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**Ms Helen Mulholland** (instructed by **Weightmans LLP**) for the **Applicant**  
**Ms Fiona Holloran** (instructed by **McAllister Family Law**) for the **First Respondent**  
**Ms Victoria Butler-Cole QC and Dr Rob George** (instructed by **Irwin Mitchell LLP**) for the **Second and Third Respondents**

Hearing dates: 19-21 May 2021  
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**Approved Judgment**

I direct that no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic. Covid-19 Protocol: This judgment was handed down remotely by circulation to the parties' representatives by email. The date and time for hand-down is deemed to be at 2.00pm on 28 May 2021.

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## Mr Justice MacDonald:

### INTRODUCTION

1. In this sad case the court is concerned with the welfare of Alta Fixsler. Alta was born on 23 December 2018 and is now 2 years and 4 months old. The question which is before the court in respect of Alta is one of the hardest of those that come before the family courts of this jurisdiction for determination. During her premature birth, Alta sustained a severe hypoxic ischaemic brain injury and was born showing no signs of life. Although she was successfully resuscitated by the medical team, it is not disputed that Alta continues to exhibit the symptoms of a catastrophic brain injury, which injury will inevitably result in her death. Alta is currently a patient at the Royal Manchester Children's Hospital Paediatric Intensive Care Unit (hereafter 'PICU') where she is receipt of intensive life sustaining treatment from an expert and dedicated medical team. This court is now asked to decide whether it is in Alta's best interests for that life-sustaining treatment to be continued. The inevitable consequence of it being discontinued will be the death of Alta.
2. The application is brought by Manchester University NHS Foundation Trust (hereafter 'the Trust'), represented by Ms Helen Mulholland of counsel. Alta is represented through her Children's Guardian by Ms Fiona Holloran of counsel. Alta's parents, are represented by Ms Victoria Butler-Cole of Queen's Counsel and Dr Rob George of counsel. The mother gave her evidence to the court in Hebrew with the assistance of an interpreter.
3. The parents are Chassidic Practising Jews and Israeli citizens. They moved to the United Kingdom in 2014. The parents tell the court that prior to these proceedings it had been their intention to return to Israel. In their first statement, the parents emphasise the fact that being devout members of the Jewish faith means that their faith is not simply a religion but is also a way of life. Within this context, the parents have sought and taken detailed rabbinical advice as to their religious duties and obligations in the context of Alta's medical situation. The parents oppose the application brought by the NHS Trust and instead seek to take Alta to Israel for continued treatment and the exploration of long-term ventilation at home in Israel in due course or, if the court concludes that it is in Alta's best interests for life sustaining treatment to be withdrawn, for that step to be taken in Israel.
4. In making the very difficult decision that is before me, I have had the benefit of expert medical evidence from Dr Martin Samuels, Consultant Respiratory Paediatrician, Dr Anthony Hart, Consultant Paediatric Neurologist and Dr Rob Ross Russell, Consultant Paediatrician. In addition, I have heard evidence from certain of the clinicians involved in the treatment of Alta, namely Dr A, Consultant Paediatric Neurologist, and Dr B, Consultant Paediatric Intensivist. I have also had the benefit of hearing oral evidence from both of Alta's parents, from their Rabbi, Rabbi Israel Goldberg, and have had benefit of a detailed and closely argued report from the Children's Guardian. The statement of the father also has exhibited to it a letter from the Chief Rabbi of Israel and a letter from Rabbi Lefkowitz. Finally, I have been greatly assisted in this challenging matter by the helpful, considered and erudite oral and written submissions of Ms Mulholland, Ms Butler-Cole QC and Dr George and Ms Holloran.

## BACKGROUND

5. As I have noted, Alta was born to the parents on 23 December 2018. Alta has one sibling, born in 2013. Alta's birth, following a pregnancy marked by reduced foetal movement and polyhydramnios, was premature and occurred by way of an emergency Caesarean section. The facts of the birth are not in dispute between the parties. Upon delivery, Alta showed no signs of life and attempts at advanced resuscitation were commenced including intubation, ventilation, IV adrenaline and ET surfactant. Alta was successfully resuscitated. Her APGAR scores were 0 at 1 minute and 2 at 10 minutes, indicating a severely compromised perinatal period. It was 20 minutes before a heart rate of greater than 100 bpm could be maintained. Following the transfer of Alta to the neonatal intensive care unit she required both artificial ventilation by way of high frequency oscillation ventilation and support to maintain her blood pressure. Further tests demonstrated signs of organ damage including acute renal impairment and, from a neurophysiological perspective, severe cortical dysfunction.
6. Given Alta's prematurity, her treating medical team waited until 10 February 2019, the date on which Alta would have been at full term, before conducting a formal assessment of the severity of her brain injury. MRI brain scans demonstrated severe multicystic encephalomalacia affecting nearly all parts of Alta's brain (meaning that extensive areas of cerebral spinal fluid now replace most of Alta's higher brain structures). Alta demonstrated symptoms of a severe hypoxic ischaemic injury in the form of a gross hypoxic ischaemic encephalopathy and severe four-limb cerebral palsy with elements of dyskinesia and spasticity. Dr A's evidence is that by March 2019 there were indications that the damage to Alta's central nervous system exceeded even some of the most severe hypoxic ischaemic encephalopathies seen in paediatric neurological practice. The parents do not dispute that Alta has suffered a severe brain injury.
7. From April 2019, a series of multidisciplinary team meetings were undertaken, at which treatment options were discussed. The parents contend that, initially, the possibility of Alta going home was discussed, at which time there was no mention of Alta being in pain. The parents further contend that only latterly did the issue of pain come to the fore, after the Trust had decided to make an application to the court. The Trust contend that palliative care was discussed with the family from the outset and that pain has likewise been an issue for Alta from the beginning. I am satisfied that it is not necessary for the court to determine which perspective is correct for the purposes of determining Alta's best interests. No agreement having been reached with respect to Alta's care, on 18 December 2020 the Trust made its application for the orders it now asks the court to make under s.8 of the Children Act 1989 and under the inherent jurisdiction of the High Court. It is now the sad duty of this court to decide those applications. Specifically, the Trust seeks the following:
  - i) A declaration pursuant to the inherent jurisdiction of the High Court that it is not in the best interests of Alta for life-sustaining medical treatment to be continued, and that it is in her best interests for a palliative care regime to be implemented;
  - ii) A specific issue order under section 8 of the Children Act 1989 (and leave to seek such an order pursuant to s.10(2)(b) CA 1989) determining that life-sustaining medical treatment should cease to be provided and a palliative care regime implemented instead.

## THE MEDICAL POSITION

### *The Overall Medical Position*

8. As I have noted above, evidence before the court demonstrates that Alta's birth injury has resulted in much of Alta's higher brain structure being eliminated. As I have further noted, MRI scans of Alta's brain show extensive multicystic encephalomalacia, although elements of Alta's cerebral cortex remain. There is a limited amount of Alta's thalami remaining and a small area of her cerebellum. In addition, the imaging of Alta's brain shows damage to Alta's brain stem, although she does not meet the criteria for brain stem death.
9. Within this context, Dr A's written evidence is that Alta exhibits the following symptoms consequent on the catastrophic brain injury she sustained at birth.
  - i) An inability to maintain an open airway and adequate ventilation to sustain life for any significant period of time without support.
  - ii) An inability to protect her airway.
  - iii) An inability to maintain core body temperature.
  - iv) An inability to blink and protect the corneal surface of the eyes, optic atrophy, an inability to perceive light and darkness and repeated ulceration of the corneas.
  - v) An inability to perceive sound due to injury to the auditory cortex.
  - vi) Sustained severe spasticity (stiffness from constant contraction of muscles) of the whole body which will increasingly lead to more permanent joint contractures (joints stuck in same position as they are always stiffly held that way by the damaged brain) and scoliosis (a bent spine).
  - vii) Spinal clonus (contracting jerks of the body triggered by the spine that is not modulated by a brain).
  - viii) Severe spasticity (requiring medication, positioning for comfort and prevention of contractures, which have already developed in some of the joints of her hands).
  - ix) An inability to swallow.
  - x) Seizures.
  - xi) Global development delay.
10. With respect to her current treatment regime, Alta is mechanically ventilated via a tracheostomy and fed by way of a feeding tube. If she is moved from her hospital bed this takes place by means of a hoist. Alta receives other interventions consequent upon her condition, including regular suctioning of her airway and the taping shut of her eyes. Alta receives the drugs Baclofen at the maximum dose to reduce the force of her spasms, Gabapentin, to reduce spasticity and pain resulting from spinal jerks and myoclonus, Trihexyphenidyl, to assist with dystonia and Diazepam, to assist with pain,

spinal myoclonus and spasticity. In his statement, Dr B states that there is no better way available to manage Alta's pain short of using sedative or analgesic agents to induce a state comparable to general anaesthesia.

### *Level of Awareness*

11. There is a consensus of medical evidence that Alta has no conscious awareness. Alta displays no positive interaction with the environment around her, is unable to close her eyes and displays no visual attention or corneal reflex and no response to auditory stimulus. The expert paediatric neurologist, Dr Hart, opines that:

“My opinion, based on her scan and neurology, is that she has no real awareness or cognitive abilities at all, but has reflex / brainstem response to distress and pain only. There is no chance of any new developmental skills being acquired. Alta is not able to have the cognitive ability to recognise people, including her family, experience pleasure, happiness or the other aspects of life that bring joy and quality to it, such as taste, cuddles, awareness of family, love and play.”

12. As I have noted, the parents do not dispute that Alta has suffered a serious brain injury and that her brain damage is at the most severe end of the spectrum. Within this context, it appears to be accepted on behalf of the parents that Alta has no conscious awareness and that Alta displays no positive interaction with the environment around her. However, in their statements, I do note that the parents contend that Alta does respond to their touch in the sense that such interactions, they contend, immediately calm her spasms. This is a matter to which I shall return.

### *Ability to Feel Pain*

13. A key issue in this case, in both a medical and a rabbinical context, is the extent to which Alta experiences pain as a result of her condition. During the course of the hearing that issue coalesced around two questions. First, to what extent is Alta exhibiting movements that, if she is able to experience pain, will cause her pain. Second, is Alta able to experience pain?
14. With respect to the first question, to what extent is Alta exhibiting movements that, if she is able to experience pain, will cause her pain, the Trust contends that Alta exhibits generalized stiffness and that, with even gentle handling, exhibits severe whole-body spasms and twitching. In her statement of evidence, Dr A states that:

“Alta is not visibly suffering and extremely distressed when she is left completely alone, with the machine helping her to breath, with her eyes covered in gel plaster and taped close to protect the cornea and when covered with a special blanket (Bear hugger) to help her maintain her temperature. The minute she is touched (for care e.g. to change a nappy or to clean her) she goes into severe whole-body spasms and shakes (spinal clonus) which will not stop unless contact stops and only after some time passes. These are very painful. The same happens when care givers try to cuddle or hug her to offer some compassionate comfort.”

Dr A did not consider that the videos provided to the court by the parents, which demonstrate periods of quietus for Alta, represent an accurate picture of Alta's presentation on the ward. When cross-examined, Dr A reiterated that, whenever she examines or handles Alta, Alta goes into immediate spasms and shudders. Within this context, whilst Dr A accepted the contents of the videos, which the court has had the benefit of watching, she maintained her view that during the great majority of interactions, Alta reacts with whole body spasms and shudders.

15. Dr B also gave evidence to the court with respect to the nature, frequency and duration of Alta's spasms from his own experience as one of Alta's treating clinicians. Dr B confirmed that he had also been able to generate a reliable and repeatable gag reflex in Alta, which he considered to be an important marker of her pain experience. In his statement, Dr B says as follows:

“There is generalised stiffness, more evident in the arms than the legs. Even the most gentle handling elicits severe whole-body spasms and twitching which persists for around 30 seconds.”

Dr B confirmed during cross-examination that each time he examines Alta she experiences such severe muscle spasms and that he had never been able to perform an examination of her that did not result in this response. Dr B further confirmed that his experience reflected that of the nursing staff who care for Alta.

16. Consistent with the evidence of the treating clinicians responsible for Alta's care, when he examined Alta on 11 August 2020, Dr Hart described Alta's reactions as follows:

“She tended to lie with her legs straight and her arms were flexed. The slightest noise, or even gentle stimulation, would lead to her arms flexing in a decorticate position. She would then generate quite a lot of clonus in her wrists and fingers. There was less movement in her lower limbs. Passive movements of her limbs revealed increased tone with a combination of dystonia and spasticity, with very marked clonus. It was difficult to get full abduction of her limbs bilaterally. Her reflexes were brisk in upper and lower limbs. There was no plantar or palmar grasp. I thought she was developing early contractures in her finger flexors, although you could just about extend the fingers fully. She clearly has contractures in her thenar eminence and her thumb is tending into palm. There were really no purposeful movements or normal movements in Alta at all. The only movements that we see appeared to be reflexes in response to stimulation.”

17. Dr Samuels likewise witnessed a similar presentation when he examined Alta five days earlier on 6 August 2020, Dr Samuels noting that Alta has no meaningful spontaneous movements, but on relatively little stimulation rapidly develops increased muscle tone or clonus and that, when he examined Alta, she readily developed upper limb spasms on minimal stimulation. Dr Samuels further noted that stimulation consistently induced repeated and prolonged tonic or clonus movements.

18. The parents dispute the contention that Alta develops spasms on minimal stimulation and on a persistent basis, and rely on their own observations, including the video clips provided to the court to which I have already referred, and on the observations of Rabbi

Goldberg. In their first statement, the parents summarise what they have witnessed of Alta's presentation in hospital as follows:

“When we have been able to visit Alta, she has always appeared to be very peaceful and settled. At times where she has been agitated or has been suffering from spasms, [the father] has soothingly placed his hand on her skin and this has caused her to settle down immediately. This has in fact been witnessed by Rabbi Goldberg and will be detailed in a separate statement by him. Alta also does not suffer spasms all of the time and not every time she is handled. We therefore do not believe that there is sufficient evidence to suggest that she is suffering constant pain or distress.”

19. The parents maintain this position in their second statement. Indeed, in that statement the parents contend that they do not believe that Alta displays *any* signs that she suffering from pain or discomfort. In his statement to the court, Rabbi Goldberg describes the situation he has witnessed when visiting Alta in hospital as follows:

“As has been set out in the statement by Mr Fixsler, they do not agree that Alta is suffering constant pain or discomfort. I have been able to attend the hospital with and without Alta's parents on several occasions where I have been able to observe her. I would agree that Alta often seems very peaceful and settled. She does not present with any signs that would suggest she is in distress or is suffering any discomfort or pain. Whilst Alta may suffer spasms when she is touched, this does not happen every time she is touched or moved and when it does happen it does not last for more than a few seconds. I have witnessed Alta respond to the touch of her parents where spasms have ceased instantly when she has been touched soothingly.”

20. On the first question of the extent to which Alta is exhibiting movements that, if she is able to experience pain, will cause her pain, the parents further rely on the reports of the expert paediatrician instructed to provide a report on their behalf, Dr Rob Ross Russell. Dr Ross Russell did not, unusually, examine Alta before preparing his first report and, accordingly, had the accounts provided by the parents and Rabbi Goldberg, the Trust's application, the statements of the treating clinicians that accompanied that application and Alta's medical records from which to form a view as to the extent to which Alta exhibits movements that could cause her pain. The parents contend that Dr Ross Russell did not visit Alta initially in part due to the impact of COVID-19 and in part due to time constraints. The Trust do not accept that Dr Ross Russell was prevented from attending by restrictions consequent on COVID-19. It is not necessary for the court to determine that dispute. In his addendum report, and having examined Alta, Dr Ross Russell concluded that “the fact that Alta does have episodes of spasm on handling, even if those do not occur every time, seems indisputable”. In oral evidence, he conceded that there are spasms and that he had made that clear to the family because there are many reports from reliable professionals. However, Dr Ross Russell also attached significance to the fact that Alta produced no response when her tracheostomy was suctioned by a nurse.

21. Finally on the first question of the extent to which Alta is exhibiting movements that, if she is able to experience pain, will cause her pain, the court has the benefit of a detailed report from the Children's Guardian, in which the Guardian observes as follows with respect to her experience of seeing Alta over a number of hours:

“During interventions to suction her tracheostomy, administer medicine or general care such as moving and handling, or even hand holding she appears to experience this all as pain and discomfort. From my non-medical visual perspective, her body, particularly her upper torso, starts to shake, until seemingly the pain reflex passes...The nurses stay with her until the pain stops, though it did not seem that their touch made the pain end but was more of a human response...”

22. With respect to the second question of whether Alta is, in fact, able to experience pain, Dr B observes as follows in his statement:

“Application of painful stimulus such as nail-bed pressure, supra-orbital pressure or trapezius squeeze, causes similar whole-body spasms and is inconsistently associated with head movement (slight rotation to the right), mouth-opening and tachypnoea. In my opinion, Alta experiences pain.”

23. Within this context, when cross-examined, Dr Hart emphasised the importance of cause and effect. Dr Hart stated that, with respect to Alta, what is seen consistently is that, when a painful stimulus is applied, a consistent response results. In this regard, Dr Hart urged the court that it is the fact that a *consistent* response to painful stimuli over an extended period of time is identified in Alta that is significant, rather than the question of whether such a response is *constant*. Dr Hart considered that this is particularly the case in the context of the variability inherent in painful stimuli, the medication being administered to Alta and level of damage sustained by Alta’s brain, which may lead to inconsistent response by reason of variability in the degree of stimulation, the amount of medication administered to Alta and inconsistent brainstem hosting of responses by reason of the level of damage Alta has sustained. Within this context, I note that when cross-examined by Ms Mulholland Dr Ross Russell conceded that, as pointed out by Dr Hart during oral evidence, during his own examination of Alta Dr Ross-Russell had not documented giving, nor had given painful stimuli to Alta, including not undertaking nail bed testing or supra orbital pressure tests. In so far as he relied on Alta’s reaction to suctioning, he based his opinion on watching a nurse undertake that activity.
24. Dr Hart also highlighted to the court the significance of the scans and EEG results for Alta. The court has before it a series of EEG reports in respect of Alta dated between 27 December 2018 and 9 January 2020. The court also has before it a Paediatric Video Ambulatory EEG Report dated 1 April 2020 which records that:

“...on many occasions throughout the recording, particularly when attended or in relation to tactile and auditory stimulation, child had episodes with stiffening, mouth opening and tremoring associated with staring lasting for many minutes.”

When cross-examined, Dr Hart confirmed that the scans of Alta’s brain indicate that a limited area of her cortex has survived and that the EEG results indicate some degree of activity in Alta’s cortex, albeit abnormal in nature. Dr Hart also considered that twitching seen in Alta in association with epilepsy indicated some surviving connections between Alta’s cerebral cortex and her muscles.



25. Within the foregoing context, in his statement Dr B says as follows with respect to the extent to which he considers Alta's reflex responses to painful stimuli are as a result of painful stimuli being *experienced* as painful by Alta:

“Whilst we can never be certain of the degree of pain experienced by children in Alta's clinical condition, I have a high degree of certainty that the consistent responses Alta demonstrates to interventions and procedures that are typically described as being painful by children who are able to express themselves, and the severe muscle spasms which she suffers, are being experienced, in some way, as pain. I would defer to Dr Grace A's excellent summary in the pain report she has produced, exhibited to this statement.”

When cross-examined, Dr B confirmed that he had cared for hundreds of children with neurological injury and, generally, response to pain is broadly consistent attenuated by the degree of neurological injury those children have suffered. In such circumstances, Dr B told the court that, from his perspective as a paediatrician seeing children who experience pain with a decreased consciousness level, when he sees a child in that diagnostic group who exhibits an attenuated version of those responses, which responses are described by children who can report their experience as being painful, he would find it difficult to say that they do not have pain. Within this context, Dr B stated in oral evidence that whilst he could not say he was certain, he considered it to be overwhelmingly likely that Alta experiences pain.

26. The pain report referred to by Dr B and prepared by Dr A constitutes a highly detailed explanation of why, from a paediatric neurological perspective and having regard to the structures in Alta's brain that remain partially intact, Dr A considers that Alta experiences pain. In the report, Dr A states that:

“The spinothalamic system is the pathway for pain. When receptors for pain in the body (these receptors are everywhere and serve all types of discomfort e.g. burns, noxious touch e.g. taping of eyelids to cheek, an itch to the nose when one cannot scratch and so the itch continues, an eyelash in the eye which one cannot tell anyone about as one is unable to and one cannot protect the eye, spasm pains in muscles which are like cramps which are so painful, pressure from lying in one position and unable to turn, bowel problems like getting constipated etc.) are stimulated these triggers an electrical signal in the nerve that passes through the spinal cord up to the brainstem nuclei and then the thalamus. The thalamus is a deep grey matter structure in the centre of the brain. This is partially preserved in Alta... In Alta we know that though both the brain stem and the thalami are damaged they are still partially functional (she is breathing and she does not fulfil the criteria for brainstem death) and so we know that the most critical structures for perception of pain (the receptors, the nerves, the spinal cord and part of the brain stem and thalami are all still present and therefore she can still perceive pain)...“It is impossible to know how much she feels”...is a correct statement. She cannot tell us and this puts even more responsibility on her carers. It is impossible to know how much a new-born feels or how much a profoundly disabled person feels but nonetheless we use all the knowledge available to us to make sure we minimise any suffering they experience...Alta definitely lacks the ability of the higher functions as her brain centres for these higher functions have been destroyed but she feels the pain. She feels pain and is unable to

protect herself from it, she is unable to understand why this pain is there, she is dependent on us to help her.”

27. Within this context, Dr A is clear in her statement of evidence to the court that she, and Alta’s clinical team, consider that Alta is in a situation of intractable pain and discomfort. Dr A considers that, in circumstances where the receptors for pain are stimulated, an electrical signal in the nerve passes via the spinal cord up the brainstem nuclei and then the thalamus and that:

“In Alta we know that though both the brain stem and the thalami are damaged they are still partially functional (she is breathing and she does not fulfil the criteria for brainstem death) and so we know that the most critical structures for perception of pain (the receptors, the nerves, the spinal cord and part of the brain stem and thalami) are all still present and therefore she can still perceive pain... Alta is able to generate a reflex to unpleasant sensations (some brain stem reflexes that she still has preserved and spinal reflexes), but she has no upper brain to derive meaning of this or any further understanding of the pain and similarly to derive any pleasure.”

When cross examined, Dr A reiterated her view that the structures that modulate sensations of pain are intact in Alta, as are the structures in the brainstem, and that Alta’s ability to experience pain is demonstrated by her reaction to stimuli that paediatric neurologists know are painful from children in a similar situation who are able to express themselves.

28. With respect to the ability of Alta’s medication to limit her spasms and her pain, Dr A made clear when cross-examined that medication can ameliorate the responses consequent upon Alta’s reflex arc but not the reflex arc itself. Within this context, her report Dr A considers that the effect of the medication is as follows:

“It is not our clinical opinion that she is not suffering when she appears peaceful and settled, it simply means that the medication is controlling some of the more distressing symptoms that she experiences and she is unable to communicate with us how much suffering that she is enduring.”

29. The expert paediatric neurological evidence provided to the court by Dr Hart reflects the views of Alta’s treating clinicians regarding the question of whether Alta can experience pain. Dr Hart is of the view that, whilst showing no signs of pleasure or enjoyment, Alta is able to experience, and is experiencing, pain. In his report Dr Hart considered that Alta has a reflex / brainstem response to distress and pain only and expressed his conclusion thus:

“The experience of pain does not require significant cognitive function. The body can produce reflexes to pain, usually mediated via the spine, that do not require cognitive function. In my opinion, Alta frequently experiences pain and discomfort most or every day. She may not have the cognitive ability to respond to this by crying or thought, but her movements and the alterations to her cardio-respiratory markers indicate that she experiences pain.”

30. In the foregoing circumstances, on the question of whether Alta can perceive pain, in oral evidence Dr Hart expressly preferred the word “experience” to the word “feel”

when addressing that question. In his report Dr Hart is clear that it is not possible to determine the *precise* nature of Alta's experience in this respect and, in particular, the extent to which that experience is akin to how those without Alta's catastrophic brain injury feel pain. In this regard, and being of the view that, for Alta, her response to pain is unlikely to be at an emotional level, in his report Dr Hart opined as follows:

"I am certain that her reflex responses are a result of pain or discomfort...Alta clearly shows reflex responses in response to painful and other stimuli that are consistent with pain or discomfort. I am certain that Alta experiences pain, but I doubt she has the cognitive ability to think or communicate about it to others. I am certain that Alta cannot experience pleasure."

31. Cross-examined carefully by Ms Butler-Cole, Dr Hart reiterated that he was certain that Alta exhibits a reaction to painful stimuli but the question of whether and how she perceives pain remains more problematic. Dr Hart stated that Alta experiences pain in some form but it is hard to quantify what that experience is and summarised his opinion thus:

"It is extremely difficult to assess levels of awareness and consciousness in a baby...Any clinician would assume a level of awareness and then look for evidence that they are not aware.... She is probably not aware of surroundings, and probably does not have an emotional response to pain although I would not be certain she does not have an emotional reaction to pain...But she shows a consistent response to painful stimulus. On balance, my view is that she has some experience of pain."

32. Dr Hart did not consider that there is a contradiction in the ability of Alta to experience pain but an inability in Alta to feel comfort and happiness. Dr Hart makes the point that pleasure is not like pain, in that pleasure is not a reflex reaction. In his report, Dr Hart sets out how he sought to explain to the parents the distinction he draws between Alta's ability to experience pain and her inability to experience pleasure:

"I don't think that Alta really has any conscious or cognitive ability to experience pleasure or joy. The movements they see when she is touched, or there is a loud noise are reflex movements. I explained this by talking about burning oneself on a kitchen hob. I explained that the body has a reflex reaction to remove the hand from the heat source, and after that point the thinking skills kick in to make an individual think 'Ouch, I must not do that again'. Alta is able to generate the reflex to unpleasant sensations, but she does not have any brain left of significance in the supratentorial compartment to have the cognitive ability to process pain further or to experience joy or happiness. When she relaxes, I don't believe that this is joy, but merely a return to resting state of being unaware of her surroundings."

33. The parents again rely on the report of Dr Ross Russell with respect to the second question of whether Alta is in fact able to experience pain. It is important to note however, that in both his first and second reports, Dr Ross Russell concedes that he is not an expert on pain and in his second report expressly defers to a paediatric neurologist on this issue. Dr Ross Russell reiterated this position in oral evidence, describing his opinion on the question of pain as "inexpert".

34. Within this context, whilst in his report Dr Ross Russell contended that given Alta's level of brain damage, signals indicating pain would not be connected to anything that allowed them to be perceived and that, accordingly, the movements exhibited by Alta do not of themselves indicate that Alta can experience pain, he also opined that if Alta were able to feel anything it would likely include painful stimuli, that children who can articulate their experience find the spasms are usually painful and certainly discomfoting and that any handling associated with spasms would be uncomfortable and probably painful. In oral evidence Dr Ross Russell agreed that parts of Alta's thalami continued to function and did not dispute the opinion of Dr Hart and Dr A that parts of Alta's cortex remained active.
35. With respect to the question of whether Alta is able to experience pain, some time was spent during the course of the evidence exploring the guidance provided by the Royal College of Physicians entitled "*Prolonged disorders of consciousness following sudden onset brain injury*" (2020). Ms Butler-Cole and Dr George submit that that guidance demonstrates that reflexive responses cannot be indicative of the experience of pain and that the guidance was taken into account by Poole J in *Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight* [2021] EWHC 25 (Fam). Poole J considered that whilst the patient group to which the guidelines apply comprises individuals aged 16 or over, it was helpful to have regard to them in circumstances where they are endorsed by a wide range of bodies including the Faculty of Intensive Medicine.
36. Dr Hart strongly rejected the suggestion that the Royal College of Physicians guidance can safely be utilised in proceedings relating to infants who have suffered a hypoxic ischaemic encephalopathy leading to cerebral palsy for the following reasons:
- i) First, the RCP guidance is promulgated in respect to persons over the age of 16 and not new-born infants.
  - ii) Second, and within this context, babies are physiologically different to adults. The brain of an infant is entirely different from that of an adult (for example the brain is unmyelinated and not completely folded). In an infant conscious awareness of environment, learning, movement are all different from an adult. The reflexes exhibited by an infant are entirely different to those seen in adults. There are reflexes that infants have that older children do not.
  - iii) Third, and again within the foregoing context, the RCP guidance implies an individual who has normal consciousness but who then loses it. Infants are in an entirely different position, with injury occurring at the very early developmental stage.
  - iv) Fourth, the RCP guidance had no paediatric input during its promulgation and comprises a consensus statement from those specialisms concerned with those over the age of 16 with PVS or MCS.
  - v) Fifth, in the foregoing circumstances, the RCP guidance is wholly unsuitable for application to infants who have sustained a birth injury with no prospect of progression.
  - vi) Sixth, the premise on which reliance on the RCP guidance is based in this case is flawed, there being *some* evidence, in the form of functional MRI data, to

show that reflexive responses in PVS patients can be a response to painful stimulus.

- vii) Seventh, paediatric knowledge is evolving all the time. What is considered the medical consensus today may not be the medical consensus tomorrow.

Within this context, Dr Hart told the court that trying to apply the “adult” model represented by the RCP guidance to an infant such as Alta is rather like giving a baby an ‘A’ level paper and then, when the baby fails to answer the questions, concluding that the baby has a learning disability.

37. Dr A also expressed surprise that the RCP guidance was being considered relevant to the position of an infant who had suffered HIE leading to cerebral palsy, describing the guidance as “totally not valid” for children. Dr B had likewise never seen the RCP guidance applied in a medical context in respect of an infant who had suffered a hypoxic ischaemic encephalopathy.

#### *Future Options for Treatment and Care*

38. There is no dispute between the parties that Alta will not recover from her injuries and that, tragically, she will ultimately succumb to those injuries. Within this context, each of the clinicians and medical experts before the court, including Dr Ross Russell instructed on behalf of the parents, consider that it is in Alta’s best interests now to withdraw life sustaining treatment and move her to a palliative care regime in circumstances where, even with the intensive care required to sustain long term ventilatory support, Alta will never recover and will have a progression of increasingly debilitating symptoms.
39. Against this, the parents advance as their primary case the transfer of Alta to Israel for continuing life sustaining treatment in hospital in Israel. In contrast to other cases in which a proposal for continued care in another jurisdiction has been advanced, the details in respect of the parents’ proposal are unhelpfully sparse. The Israeli doctors, who it is envisaged by the parents will care for Alta in the event of her transfer to Israel, have not examined Alta nor have they requested facilities to do so. It is unclear whether they have fully considered her medical records and they have not yet spoken to the Trust’s clinicians. There is no written material from the medical institutions in Israel other than the two scant documents which are exhibited to Mr Fixsler’s statement, which confirm an apparent willingness on the part of director of the Herzog Medical Centre, Dr Yehezkel Caine and the Head of Paediatric Critical Care at the Hadassah Medical Centre, Dr Uri Pollak, to admit Alta as a patient. There is no evidence from the Israeli hospitals as to the treatment regime that would be implemented were Alta transferred to Israel and neither document deals in any way with the medical logistics of transfer or treatment plans, although there is confirmation that the parents have identified an air ambulance service willing to transport Alta. Whilst the Herzog Medical Centre in Jerusalem has agreed to accept transfer of Alta, this is said to be subject to her being stabilised at the Hadassah Medical Centre. The reason for this requirement, which introduces an additional move for Alta, is not dealt with in the documents provided by the parents.
40. There was no dispute between the treating clinicians and medical experts that the increased need for movement, care interventions and changing environments associated

with a transfer will cause additional discomfort for Alta in circumstances where she would not be travelling for medical benefit. Dr Hart was clear in his oral evidence that a transfer would cause Alta pain in circumstances where she would experience spasms and pain at points of movement, for example from her bed to a trolley and from trolley to a plane, again for no medical benefit. With respect to whether transfer could be effected without causing additional pain to Alta, Dr B says in his second statement of evidence that:

“No. Even the most minimal handling of Alta triggers painful muscle spasms and dystonia. A transfer involving at least two ambulance transfers and air transfer of around 4000km would inevitably cause considerable additional pain and suffering even with the administration of sedative and analgesic agents. Such a transfer will be of no benefit for Alta and cannot be supported by the clinical team.”

41. Dr Ross Russell conceded that, if the court accepts that Alta can experience pain then a transfer will be uncomfortable for Alta. Dr Samuels considered the question of transfer and concludes as follows in his report to the court:

“Transfer of Alta to another unit in the UK or abroad is a significant risk for an adverse event, including unpredictable deterioration and death. It will be associated with increased movements, care interventions and changing environments, all of which may result in additional discomfort or pain for Alta. These could be mitigated by strong sedation and pain relief or anaesthesia, but such an approach is not without risk itself. She would not be travelling for the purposes of receiving beneficial treatments, that increase her chance of recovery. There is no chance of recovery. The impact on Alta would be wholly negative and not in her best interests.”

And

“There are risks if Alta were to be moved, including: a risk of stressing her and increasing her spasms; moving secretions and worsening her breathing problems; making her temperature control more difficult; and, the risks of her deteriorating in a non-critical care environment. While careful planning for escalation of care, use of senior staff, and strong sedation/anaesthesia may all mitigate these risks, it is unclear that there is any benefit from undertaking such a move with the risks that this poses. She will not receive care or treatment that aids her recovery, and her extensive brain injury will remain.”

42. With respect to the transfer itself, Dr Ross Russell considers that the risk of mortality for Alta attached to that of transfer to be less than 5%. Dr Samuels however, placed the figure as 20% in circumstances where Alta has a very limited respiratory reserve. Within this context, Dr Samuels emphasised that doctors try to avoid moving seriously ill children unless it is of medical benefit.
43. Finally, this case, and the parents primary submission that it is in Alta’s best interests to be transferred to Israel, has been advanced in the wider context of an outbreak of hostilities between Israel and Hamas, impacting on Israel and Gaza. The court did not hear evidence with respect to the risks, if any, presented by the transfer of Alta in the context of ongoing hostilities, although a letter provided by the parents from the air

ambulance service that they propose to employ dated 19 May 2021 confirms that medical flights into Israel have continued notwithstanding the conflict. Further, the final day of the final hearing on 21 May 2021 coincided with the announcement that a ceasefire had come into effect between Israel and Hamas. Within this context, I have not found it necessary to examine the impact of the current political and military situation in Israel in determining this case.

### *Prognosis*

44. It is accepted by all parties that there is no prospect that Alta will recover from her catastrophic brain injury. With respect to how long Alta may survive, the tenor of the evidence received by the court is that the position is necessarily uncertain. Each of the medical witnesses emphasised the inherent unpredictability in Alta's situation and the difficulty in giving an accurate estimate of life expectancy within that context. The estimates that were provided by the expert medical witnesses ranged from six to twelve months in the opinion of Dr Ross Russell (he having revised his original estimate that Alta would live to between the age of six and eight after he had examined Alta prior to authoring his addendum report) and 12 to 24 months in the opinion of Dr Hart. Dr Samuels was of the view that it is difficult to give a reliable prognostication with much depending on level of care doctors are willing to escalate to. Each of the medical experts repeatedly stressed the difficulty in reaching any reliable conclusion as to life expectancy with respect to a child in Alta's condition. The parents accept that Alta's life will end in her childhood years.
45. The question of prognosis is not simply one of life expectancy for the purposes of the application of the best interests test in the current case. In addition to the question of lifespan, the court has also heard evidence of the extent to which, and the manner in which Alta is likely to deteriorate over the course of her shortened lifespan. In this respect, the report of Dr Hart concludes as follows:

“Alta's life is being sustained with ventilatory support via tracheostomy. Should this continue, my opinion is that Alta's symptoms are going to worsen, and she will accumulate further comorbidities that would be deeply unpleasant and painful for her. These will include (but are not exclusive of):

- (a) Repeated lower respiratory tract infections and worsening respiratory function (I note that she is considered not to be a candidate for long term home ventilation);
- (b) Worsening dystonia and spasticity with associated pain;
- (c) Hip dislocation and pain;
- (d) Scoliosis, which may be painful and could lead to further suppression of respiratory function;
- (e) Gastroesophageal reflux disease;
- (f) GI failure secondary to dysmotility;
- (g) Pressure sores;
- (h) Ongoing problems with corneal abrasions and ulcers;
- (i) Worsening epileptic seizure;
- (j) Continued problems with management of secretions in her oropharynx and risk of aspiration;
- (k) Risk of other infections to body systems, including urinary tract infections;

- (l) Craniosynostosis;
- (m) Blindness / severe visual impairment;
- (n) Corneal abrasions and ulcers.”

*Best Interests*

46. The unanimous view of Alta’s treating clinicians, and the experts instructed by the Trust, is that it would be in Alta’s best interests for life-sustaining treatment (including artificial ventilation) to be withdrawn and for her to receive palliative care only. This view is shared by Dr Ross Russell. In his oral evidence he confirmed that he could not support transfer to Israel for the purpose of life sustaining treatment. On this issue, Dr Hart expresses himself thus in his report:

“In my opinion, Alta’s care should be redirected towards palliation and comfort care. She fulfils the criteria set out by the Royal College of Paediatrics and Child Health in the article by Larcher et al in Archives of Disease of Childhood 2015, in that her quality of life is severely limited. The burdens of treatment are going to produce pain and suffering that would outweigh any potential benefits. The burden of her underlying condition is severe, and is producing pain and distress, and current and future medical interventions are not going to be of benefit to Alta or in her best interests.”

47. The comprehensive and closely analysed report of the Children’s Guardian also concludes that it is Alta’s best interests for life sustaining treatment to be withdrawn. The Children’s Guardian makes clear in her report that her conclusion is informed by the following factors she considers relevant to the best interests evaluation:

- i) Alta spends all her time in a paediatric intensive care cubicle. There is no window and she is the subject of constant medical supervision and intervention by nurses in full PPE on a 12 hour rota. Alta has had no skin to skin contact for over a year. She is connected to monitors which sound regularly when she is in distress.
- ii) Alta is ventilator dependent and experiences ventilatory arrest several times a day both spontaneously and during care activities such as nappy changes.
- iii) Alta has had and continues to have very limited contact with her parents, in part for reasons that the court is aware and which need not be detailed in this judgment and in part by reason of a conscious decision on the part of the parents. Alta’s life is currently devoid of expressions of love and attention from her kin. Alta is alone in the world and no family or friends have any real connection with her. Even if Alta was able to experience pleasure, which is the parents’ position, they have not been there to offer it to her.
- iv) Alta has no awareness and no means of communicating with the wider world.
- v) From a lay perspective, during interventions to suction her tracheotomy, administer medicine or general care such as moving and handling, or even hand holding she appears to experience this all as pain and discomfort.



- vi) Alta is not able to express wishes and feelings but it is evident that due to the most severe and debilitating of health conditions her day to day life is characterised by repeated life sustaining intervention and medical care that ultimately causes her pain and suffering.
  - vii) Medical improvement is not possible for Alta and her life is, and will continue to be, characterised by the intervention and techniques that are necessary to support her to stay alive. There is no prospect of recovery and therefore there is no benefit to her of her suffering as it will not lead to an improvement or a lessening of that suffering in the future.
  - viii) Recognising the benefits and comforts that many people obtain from having religious beliefs by which they live their lives, these are not benefits and comforts which Alta has been able to enjoy. She is unaware of her faith and is not and never will be in a position to derive solace from enduring suffering because it is in accordance with her spiritual beliefs.
  - ix) Alta has no quality of life. The burdens of Alta's life outweigh any benefits that the Children's Guardian has been able to ascertain.
48. Within the foregoing context, the Children's Guardian also does not consider it to be in Alta's best interests to be transferred to Israel for continuing life sustaining treatment, nor for the purposes of withdrawing that treatment should the court decide that that is in Alta's best interests.

#### *The View of the Parents*

49. As I have noted, the parents dispute the assertion that Alta experiences pain. Within this context, and having regard to their religious duties and obligations and the rabbinical advice they have received, they cannot, and do not, accept a palliative pathway for Alta's care. It is also clear that the parents' position is informed by factors additional to their deeply held religious convictions. As I have noted, the parents consider that the medical staff involved with Alta's care have performed an unjustified volte-face in circumstances where they consider that, when Alta was under the care of a previous treating clinician, she demonstrated a consistent and continuing respiratory drive, treatment at home was being considered and the question of pain was not raised but that, following a change of treating clinicians, it is now considered that treatment should be withdrawn and pain is now being used by the Trust to justify their application. An assertion roundly rejected by the Trust.
50. With respect to the religious aspect of the parents' objections, the father's statement makes clear that as Chassidic Practising Jews the parents are Ultra-Orthodox and practise religion with traditional values and without compromising on any matter that contradicts the true Torah values and guidance. Within this context, the father informs the court in his statement that the parents have received rabbinical advice that it would be contrary to their Jewish faith to adopt a palliative care pathway. In their first statement, the parents' summarise the position they take having regard to their faith as follows:

“We are practicing Ultra-Orthodox Jews who adhere to what we are instructed to do in line with the Torah and Jewish faith. We are taught that

life is sacred and not only must we preserve life, we also cannot be involved in bringing death closer. We have contemplated this at great length and we have had the benefit of rabbinical support and advice. In our faith we consider that if somebody could live for at least 12 months and that that it cannot be proven that they are suffering constant pain, then it ultimately makes no difference whether they might live for a further 12 months or a further 70 years. They are regarded as being alive and there must not be any steps taken that would shorten a life. In our faith, it is strictly forbidden to actively shorten a life. The only circumstances under which this might be permissible is where somebody is in constant suffering and pain, but we do not believe that these circumstances apply to Alta.”

51. Within this context, in his statement to the Court, Rabbi Goldberg helpfully articulates the relevant tenets of the Jewish faith as they inform the position taken by the parents with respect to the application of the Trust as follows (making clear that there is a difference of view with respect to these matters as between a number of rabbinical authorities):

“[9] It is important to understand that the Jewish faith is a way of life with directives from our Torah that was given to Moses with values and beliefs that affect all aspects of life. A central value of the Jewish faith is the sanctity of life, as opposed to the quality of life. This is a fundamental Jewish belief that human life, no matter how compromised, is invaluable. Therefore, the commandment to observe the Sabbath and almost all other religious laws may be violated to protect or save a life and even to extend life for a brief period of time.

[10] There is thus a widespread perception that Jewish law, mandates that all measures be taken to extend a dying person’s life regardless of financial cost, emotional burden to the family, and prolonged suffering of the patient. This is the perception within much of the Orthodox Jewish community and among medical health professionals. In truth the well-established and majority position of the authorities of Jewish law is that, in certain cases of a terminally ill patient, such life-extending measures are not mandated.

[11] In addition to a duty to preserve life, Jewish law also recognizes a duty to alleviate suffering. The Talmud states that extreme suffering can be a fate worse than death. The question then becomes how one is to balance the duty to preserve life when it conflicts with the duty to alleviate suffering.

[12] A number of rabbinic authorities assert that the duty to protect life is paramount in all situations. They require any and all life-extending measures be taken. However, others rule that one should allow natural death to take its course, and that one is not required to intervene in such a case.

[13] Whilst this has been framed in terms of balancing the obligation to prolong life against the obligation to alleviate suffering, we will see that it may also be framed as the difference between prolonging life and postponing death. Suffering aside, Jewish law may mandate that we do not obstruct a natural death from running its course. This is an additional reason to allow

or require non-interference in the case of an unconscious terminally ill patient.

[14] The position that one need not administer life-prolonging treatment for a terminally ill patient is limited to the passive non-administration of treatment. To actively shorten a life, either directly or indirectly, is strictly forbidden regardless of life expectancy, mental state, or capacities of the patient. Euthanasia is considered murder, and assisted suicide is indirect murder.

[15] From the medical perspective there is no difference between withdrawing treatment and choosing not to administer it in the first place. However, from the perspective of Jewish law, the withdrawing of certain treatments can be tantamount to actively hastening death.

52. In oral evidence, Rabbi Goldberg told the court that, faced with challenge of health matters, the rabbinical authorities must reflect on the Talmud and the Mishna and attempt to marry them with modern medicine. Rabbi Goldberg further informed the court that, in addition to the fact that Jewish law prohibits the withdrawal of treatment in the circumstances articulated above and that the parents would be committing a grave sin if they agreed to or allowed such a course, such action would also have adverse spiritual consequences for Alta, Rabbi Goldberg telling the court that:

“For Alta, a crucial factor is whether she fulfils her purpose in life on Earth: if she passes away without any human intervention she fulfils her role and can go to Heaven. If we intervene, we might interrupt that process”

Rabbi Goldberg further explained that the spiritual consequence of this is that there is a risk of reincarnation in this world, rather than passing to Heaven:

“The soul can come down into another body, which generally happens if the previous soul didn’t fulfil a full role and has things still to do to perfect before they can go to heaven”

53. In addition to the importance of cemeteries being proximate for the process of mourning for the parents and the family, Rabbi Goldberg was concerned about the spiritual consequences for Alta if it was not possible to *properly* perform the required burial rites in respect of Alta following her death, both in terms of the timing of her burial, which under Jewish law must take place as soon as possible, and the possibility of her not being able to be buried in Israel:

“The majority of God fearing Jews would like to be buried in Israel. The first to come back [on the day of judgment] will be those buried in Israel. Those who are further away will have to go through suffering before coming back to Israel.”

Whilst conceding that it would be possible to transport Alta’s body for burial in Israel, Rabbi Goldberg informed the court that the teaching on the meaning of the Torah:

“says that a person who has lived abroad and is then brought to Israel after death can create problems, because if the person did not live in Israel there

may be contamination and the burial may not be perceived as so prominent or important as if the person had lived their last days in Israel, so if possible the person should live their last days in Israel.”

54. Appended to the parents’ statement is a letter dated May 11 2021 from the Chief Rabbi of the State of Israel and President of the Great Rabbinical Court. This court is grateful to the Chief Rabbi for giving the court the benefit of his Halachic opinion. Within the letter to the court, the Chief Rabbi opines as follows:

“In the given situation, the cessation of the ventilator will bring her closer to her death, and that is forbidden. If there is further development in the disease that will cause the need to add life-saving actions to revive her, it may be permissible to not take those acts, but to stop treatment that saves lives - is forbidden.

There is another question that arises from this case, the question of suffering and pain. This is an unclear issue, there is no clear information about what the girl is actually able to feel, and it is very possible that the brain injury is so severe that there is no pain and suffering.

With this in mind, I appeal to you to not aggravate the grief of the parents, who are Orthodox Jews living according to the Halacha, which is their guiding principle in life, to accept their request and reject the doctors request for euthanasia. This case, in our opinion is not included in the definition of euthanasia.

I should add that according to the Israeli law, the Dying Patient Act, given the medical condition of the girl the parents have a right to demand life-prolonging treatment.”

55. Applying the foregoing principles, the rabbinical authorities from which the parents have sought advice, or from whom advice has been sought on their behalf by Rabbi Goldberg, are clear that in the circumstances that apply to Alta it is not permissible under Jewish Law for her parents to consent to the withdrawal of her medical treatment and that her life must be preserved. Within this context, whilst certain rabbinical authorities admit of the possibility of the withdrawal of treatment in circumstances of *extreme* suffering, the parents contend that Alta is not suffering intense pain or discomfort, the parents consider and submit to this court that Jewish law prohibits the withdrawal of life sustaining treatment from Alta and that for them to consent to such a course of action would be to fail to fulfil their religious obligations as Ultra-Orthodox Jews.

## LAW AND GUIDANCE

### *Law*

56. The court may grant a declaration declaring that treatment in accordance with the recommendation of the child’s doctors can take place, on the grounds that it is in the child's best interests (see *Re B (A Minor)(Wardship: Medical Treatment)* (1982) 3 FLR 117). The jurisdiction of the court to make such an order arises where a child lacks the capacity to make the decision for him or herself, in the context of a disagreement

between those with parental responsibility for the child and those treating the child (*An NHS Trust v MB* [2006] EWHC 507 (Fam)). The court has no power to require doctors to carry out a medical procedure against their own professional judgment.

57. As I have observed in previous cases, the legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not ‘*Gillick*’ competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:

- i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents’ duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.
- ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient’s attitude to treatment is or would be likely to be.
- iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term ‘best interests’ is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

“This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism.”
- iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child’s best interests.
- v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.

- vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment.
- vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.
- viii) Each case is fact specific and will turn entirely on the facts of the particular case.
- ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB Holman J*, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

“The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.”

- x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.

58. These principles have been reiterated repeatedly at appellate level. In *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:

“[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it.”

And

“[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.”

59. In the case of *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410, McFarlane LJ again reiterated that:

“As the authorities to which I have already made reference underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view.”

60. It is necessary however, to deal in a little more detail in this case with the nature and application of the best interests test in this case in light of the submissions made on behalf of the parents by Ms Butler-Cole and Dr George.

61. Perhaps inevitably, given its superficial similarities with this case, my attention has been drawn by Ms Butler-Cole and Dr George to the decision of this court in *Tafida Raqeeb v Barts NHS Foundation Trust and others* [2020] 3 All ER 663. Before turning to the submissions made on behalf of the parents in this context, it is important to note that *Tafida Raqeeb v Barts NHS Foundation Trust and others* is a decision taken, as the court is required to do in all cases of this nature, on its own very particular facts. Further, I endorse the observation of Hayden J in *Birmingham Women’s and Children’s NHS Foundation Trust v JB* [2020] EWHC 2595 (Fam) at [30] that, contrary to the arguments advanced in the paper entitled *Making Decisions for Children—Accommodating Parental Choice in Best Interests Determinations : Barts Health NHS Trust v Raqeeb*, Cave, E; Brierley J; Archard D. *Medical Law Review*, Vol. 28, No. 1, pp. 183; 196, the decision of this court in *Tafida Raqeeb v Barts NHS Foundation Trust and others* does not seek to sever medical best interests from an overall evaluation of the child’s best interests as required by the legal principles set out above.

62. Within this context, with respect to the decision of this court in *Tafida Raqeeb v Barts NHS Foundation Trust and others* it is important once again to note the concluding observation made by this court at [191]:

“[191] Within this context, and particularly where a child is not in pain and is not aware of his or her parlous situation, these cases can place the objective best interests test under some stress. Absent the fact of pain or the awareness of suffering, the answer to the objective best interests test must be looked for in subjective or highly value laden ethical, moral or religious factors extrinsic to the child, such as futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, which factors mean different

things to different people in a diverse, multicultural, multifaith society. Nevertheless, the gold standard against which cases of this nature are measured and determined remains that of the child's best interests and as the march of medical innovation continues to bring cases of this nature before the courts the courts will be required to apply this standard to the best of their ability. That is what I have endeavoured to do in this very sad case."

63. In their Position Statement prepared on behalf of the parents, Ms Butler-Cole and Dr George submit however, that what the foregoing passage from *Tafida Raqeeb v Barts NHS Foundation Trust and others* does highlight is the fact that, with respect to the overall evaluation of the child's best interests as required by the legal principles set out above:

"While there is a broad international consensus around the concept of best interests (this is seen most prominently in Article 3(1) of the UN Convention on the Rights of the Child 1989) there are widely varied conceptions of what that term means. Put another way, one should 'begin ... by cautioning against the assumption that there is only one best interests standard in currency' (S Parker, 'The Best Interests of the Child – Principles and Problems' (1994) 8 International Journal of Law and the Family 26, at p 27). Thus, while it is no doubt in one sense right that 'there can only logically be one best option' when making a decision about a child's best interests (*Aintree University Hospital NHS Trust v James* [2013] UKSC 67, [2014] AC 591, para 24), the assessment of which option is that logically single best option depends on the criteria by which one assesses 'best', and those criteria and the weight to be attached to them are not universal or objective."

64. Within this context, Ms Butler-Cole and Dr George submit that in the assessment of overall best interests the law permits, and indeed requires an appreciation on the part of the decision maker about the cultural context of the individual about whom the decisions are being made. In support of this submission, Ms Butler-Cole and Dr George cite the conclusions of Professor Alston in 'The Best Interests Principle: Towards a Reconciliation of Culture and Human Rights' ((1994) 8 International Journal of Law and the Family 1, at p 5) that whilst the principle that the child's best interests should be paramount is a principle found across the world:

"[t]his apparent commonality contrasts sharply, however, and potentially very revealingly, with the very diverse interpretations that may be given to the principle in different settings."

And the conclusions of Professor Auckland and Professor Goold in 'Re-Evaluating 'Best Interests' in the Wake of *Raqeeb v Barts NHS Foundation Trust & Anors* ((2020) 83 Modern Law Review 1328) regarding the difficulties in applying the best interests test where disputed factors relevant to that test admit of more than one reasonable view as to best interests.

65. Within this context, Ms Butler-Cole and Dr George highlight, by way of example, this court's analysis in *Tafida Raqeeb v Barts NHS Foundation Trust and others* of the role of dignity in the best interests decision in cases of this nature:



“[176] I have also paid careful regard to the Trust's submission that even if Tafida feels no pain, further invasive treatment over an extended period of time will impose an unacceptable burden on her human dignity, which burden will be increased as she develops further debilitating physical symptoms. Again, I accept that within the context of the frame of reference advanced by the Trust, namely continued invasive medical treatment over many years with little recuperative benefit may, for example in the manner articulated in Bland, reach the point of indignity for Tafida. The concept of human dignity as an element of the best interests analysis is however, not without difficulty. The term 'human dignity' does not lend itself to precise definition and there is no universal agreement as to its meaning. The concept of human dignity must, accordingly, contain a significant element of subjectivity and thus be influenced by, for example, the religious or cultural context in which the question is being considered. In *M v N* [2015] EWCOP 76 at [72] Hayden J observed that:

"There is an innate dignity in the life of a human being who is being cared for well, and who is free from pain. There will undoubtedly be people who for religious or cultural reasons or merely because it accords with the behavioural code by which they have lived their life prefer to, or think it morally right to, hold fast to life no matter how poor its quality or vestigial its nature. Their choice must be respected. But choice where rational, informed and un-coerced is the essence of autonomy. It follows that those who would not wish to live in this way must have their views respected too."

[177] Within this context, the question of whether continued treatment would burden Tafida with indignity falls to be considered, once again, in the context of the agreed evidence that, ultimately, whilst moribund, with minimal awareness and entirely dependent on the care of others, it will be possible for Tafida to be cared for at home by a loving and dedicated family and consistent with the religious code and community values within which she had been raised. In the context of the concept of human dignity, although difficult to define, I am satisfied that this is a significantly different proposition to, for example, continued care over a period of years confined in a Tier 2 ICU unit.”

66. In the foregoing circumstances, and pointing out this court’s observation in *Tafida Raqeeb v Barts NHS Foundation Trust and others* that this jurisdiction does not hold the monopoly on legal and ethical matters, Ms Butler-Cole and Dr George submit that it is not only appropriate, but imperative, that an assessment of the various dimensions of Alta’s best interests must take into account particular religious, cultural and ethical context of this case provided by the fact that Alta is an Israeli citizen, the fact that the family intended to emigrate with Alta to Israel and the family’s Orthodox Jewish beliefs and cultural values. Further, Ms Butler-Cole and Dr George contend that whilst the right to freedom of religion of a family under Art 9 of the ECHR may be circumscribed where it conflicts with the child’s best interests, the assessment of what those best interests are in the first place must be informed by these considerations, and by a recognition that religious and ethical frameworks governing these sensitive matters differ. Within this context, Ms Butler-Cole and Dr George submit that the assessment

should start from the assumption that Alta would share the values of her parents, of her brother, and of her wider family and community.

67. The difficult issue of the role of subjective or value laden ethical, moral or religious factors extrinsic to the child in the best interests decision was most recently considered by Poole J in *Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight* [2021] EWHC 25 (Fam) and by the Court of Appeal in the subsequent appeal in *Paula Parfitt v Guy's and St Thomas' Children's NHS Foundation Trust and Pippa Knight* [2021] EWCA Civ 362. At first instance, Poole J expressed caution regarding the consideration of “impalpable factors” (a term used by Lord Browne-Wilkinson in *Airedale NHS Trust v Bland* [1993] AC 789). Within this context, Poole J observed at [86] as follows regarding this court’s use in *Tafida Raqeeb v Barts NHS Foundation Trust and others* of the concept of dignity as a factor in the best interests analysis:

“The concept of "dignity" to which MacDonald J referred in *Raqeeb* at [176] to [177] (above) and which has influenced the view of Dr B, is, I believe, problematic and does not assist me in identifying what is in Pippa's best interests. In an adult or older child the concept of dignity might be linked to their exercise of autonomy and be a crucial factor in determining what is in their best interests, but that factor does not apply in the case of a young child like Pippa, whose values, beliefs, and wishes cannot reliably be ascertained or inferred. Perhaps we all think we can recognise human dignity when we see it, but there is obviously a high degree of subjectivity involved in describing someone's life or death as having dignity .... There is a wide range of opinion as to what constitutes a dignified death .... I take into account the views of Pippa's mother and of others about her best interests, but given the very different ideas expressed to the court about what would constitute dignity for Pippa in life and in her dying, I shall not presume to adopt some supposedly objective concept of dignity to determine her best interests.”

68. When the case came before the Court of Appeal the contrary view was argued but the Court of Appeal did not consider it necessary to decide the point for the purpose of disposing of the Appeal:

“[98] On behalf of the appellant, Mr Sachdeva observed in oral submissions that dignity was not, as he put it, the touchstone. In his submissions on behalf of the guardian, however, Mr Davy made extensive submissions about the concept of dignity and its role in decisions concerning the withdrawal of life-sustaining treatment. It was his contention that, in addition to the principle of the sanctity of life and principle of self-determination, the court in these circumstances should take into account the principle of the respect for the dignity of the individual. He submitted that the judge was correct to identify amongst the factors relevant to his decision both the burdens arising from the intensive and intrusive treatment required to keep Pippa alive and her grave loss of function and the potential benefits to be gained from treating her at home surrounded by her loving family rather than in hospital. Mr Davy submitted, however, that the real justification for including these burdens and benefits is that they are both aspects of the principle of respect for the dignity of the individual. He argued that this principle requires respect for an individual's value as a human being and encompasses both their psychological and physical integrity being deemed worthy of respect.

Somebody who has no awareness of their circumstances can still be afforded dignity, or treated with indignity, by the manner in which they live and the way in which they are treated. Mr Davy submitted that, in Pippa's case, there is an innate indignity and burden associated with the intensive and intrusive treatment required to keep Pippa alive and her grave loss of function. Alternatively, if she were able to be cared for at home surrounded by her loving family, this would be a less undignified existence than her current care within the PICU. Notwithstanding these submissions, however, the guardian concluded that, when all the factors relevant to the decision are taken into account including the three principles of sanctity of life, self-determination and respect for the dignity of the individual, the potential benefit to Pippa from being cared for at home did not come close to tipping the best interests balance.

[99] Mr Davy developed these arguments by reference to a number of reported authorities, in particular the decision of the House of Lords in *Airedale NHS Trust v Bland* [1993] AC 789 . I commend him for the thought and care with which he has prepared those submissions and I intend no disrespect to him in saying that I do not think it necessary or appropriate on this occasion to embark upon a detailed analysis of the arguments he deployed. The judge declined to attach any weight to the concept of dignity in reaching a decision about Pippa's best interests...Neither the appellant nor the Trust has sought to argue that he was wrong in adopting that course.

[100] Other judges, dealing with cases involving different circumstances, have taken a different approach: see for example MacDonald J's decision in *Raqeeb*. In a future case, it may be necessary for this Court to address arguments akin to those put forward by Mr Davy about the role played by the concept of dignity in decisions of this sort. That necessity does not arise on this appeal.”

69. Having considered carefully the submissions of Ms Butler-Cole and Dr George, I am satisfied that the legal principles governing the determination of cases of this nature remain well settled. The approach to evaluating best interests in cases of this nature is that set out in the clear line of authority summarised at paragraph [57] above, and Ms Butler-Cole and Dr George did not seek to suggest otherwise. The task of the court is to identify what is in the subject child's best interests. It is well established that the concept of best interests is used in its *widest* sense and will include every kind of consideration capable of bearing on the decision and not limited to, medical, emotional, sensory and instinctive considerations.
70. Within this context, the judgment of this court in *Raqeeb* sought to recognise that some of the wide range of considerations relevant to the evaluation of best interests, such as the role of religious belief, futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, will be ones that admit, as the best interests principle itself can admit, of more than one “right” answer capable of driving the best interests decision of the court, particularly in the absence of factors which tend to attract societal consensus, such as the undesirability of pain and suffering. However, and consistent with the long-established process of evaluation conducted by the court with respect to best interests, whether, in a given case, those more subjective or value laden

factors will drive the best interests decision will depend on the *totality* of the welfare factors that fall to be considered in that case.

71. In these circumstances, I have no hesitation in accepting the submission that an assessment of the various dimensions of Alta's best interests must take into account the particular religious, cultural and ethical context of this case provided by the fact that Alta is an Israeli citizen, the fact that the family intended to emigrate with Alta to Israel and the family's Orthodox Jewish beliefs and that the assessment of her best interests must be informed by consideration of the religious and cultural values of the family, and by recognition that religious and ethical frameworks governing these subjective factors differ (which reflects the position set out in the RCPCH Guidance set out in *Larcher V, et al. Arch Dis Child* 2015;100 (Suppl 2): s1–s23)).
72. However, within the well-established legal framework summarised above, such matters remain at all times simply factors to be placed into the *overall* best interests evaluation, which factors may or may not drive the outcome of that evaluation depending on the nature and strength of all of the other factors, both medical and non-medical, that fall properly to be placed in the best interest analysis on the particular facts of the case. Within this context, I reject the submission of Ms Butler-Cole and Dr George that "the best interests decision-making process can and must be framed within the Jewish belief system in this case." Rather, the Jewish belief system followed by the parents is *one* factor to be weighed in the balance by the court when reaching a best interests decision. For reasons I will come to, I am likewise not able to accept the submission that the assessment of Alta's perspective should start from the assumption that Alta would share the values of her parents, of her brother, and of her wider family and community.

### *Guidance*

73. In addition to the case law I have set out above, the guidance issued by the Royal College of Paediatrics and Child Health entitled '*Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice*', published in March 2015 is of assistance in navigating the question of the child's best interests in these most difficult of cases. With respect to the issues raised in this case, the Guidance states as follows with respect to the sets of circumstances when treatment limitation can be considered because it is no longer in the child's best interests to continue, as treatments cannot provide overall benefit:

#### **"I When life is limited in quantity**

If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These comprise:

- A. Brain stem death, as determined by agreed professional criteria appropriately applied;
- B. Imminent death, where physiological deterioration is occurring irrespective of treatment;
- C. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

## **II When life is limited in quality**

This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with illness or treatment itself. These comprise:

- A. Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits;
- B. Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life;
- C. Lack of ability to benefit; the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life."

74. In respect of circumstances where life may be of limited quality due to a lack of ability to benefit from continued life, the Guidance provides further illumination as follows:

### **"C. Lack of ability to derive benefit**

In other children the nature and severity of the child's underlying condition may make it difficult or impossible for them to enjoy the benefits that continued life brings. Examples include children in Persistent Vegetative State (PVS), Minimally Conscious State, or those with such severe cognitive impairment that they lack demonstrable or recorded awareness of themselves or their surroundings and have no meaningful interaction with them, as determined by rigorous and prolonged observations. Even in the absence of demonstrable pain or suffering, continuation of LST may not be in their best interests because it cannot provide overall benefit to them. Individuals and families may differ in their perception of benefit to the child and some may view even severely limited awareness in a child as sufficient grounds to continue LST. It is important, here as elsewhere, that due account of parental views wishes and preferences is taken and due regard given to the acute clinical situation in the context of the child's overall situation. Although it is possible to distinguish these different groups of decisions to limit LSTs that are based on quality-of-life considerations, in practice combinations may be present. For example, a child or infant in intensive care may have sustained such significant brain injury that future life may provide little benefit, while both intensive treatment and future life are likely to cause the child substantial pain and distress."

75. As I have noted, in this case, the court has also heard evidence and argument regarding the significance of the guidance issued by the Royal College of Physicians entitled *Prolonged disorders of consciousness following sudden onset brain injury*, the updated version of which was authored in 2020 and deals with those in a vegetative state (VS) and a minimally conscious state (MCS).
76. The RCP Guidance defines VS as a state of wakefulness without awareness in which there is preserved capacity for spontaneous or stimulus- induced arousal, evidenced by sleep-wake cycles and a range of reflexive and spontaneous behaviours and characterised by complete absence of behavioural evidence for self or environmental awareness. MCS is defined as a condition of severely altered consciousness in which

minimal but clearly discernible behavioural evidence of self or environmental awareness is demonstrated and is characterised by inconsistent, but reproducible, responses above the level of spontaneous or reflexive behaviour, which indicate some degree of interaction with their surroundings. The evidence and argument with respect to the guidance issued by the RCP centred on the extent to which reflexive behaviours indicate an ability to experience pain. Within this context, I also note the following relevant extracts from the guidance as follows at [2.6]:

“Even though patients in VS are considered to be unaware, and therefore unable to experience the emotional consequences of pain, they may display physiological signs suggestive of pain. For example, several authors have demonstrated that, although there is some relationship between pain scores and level of consciousness assessed using the CRS-R, the relationship is not entirely robust. Pain is a primitive response and it appears that at least some patients who are behaviourally in VS at least respond to pain and so may be able to perceive it.”

And with respect to the significance of reflexive activity undampened by cortical inhibition [2.6.1]:

“In the context of PDOC, behaviours that are normally associated with pain may occur spontaneously as a result of reflex activity undamped by cortical inhibition, so the signs must be interpreted with caution. Further, changes associated with spontaneous or induced sympathetic over-activity (usually associated with hypothalamic damage) will give rise to signs similar to those induced by pain.”

## DISCUSSION

77. With deep sorrow, I have decided that it is in Alta’s best interests for life-sustaining medical treatment now to be withdrawn, and for a palliative care regime to be implemented and that the application of the Trust must therefore be granted. The reasons for my decision are as follows.

### *Alta’s Medical Condition and Prognosis*

78. There is no dispute between the parties that Alta has sustained a catastrophic brain injury from which she will not recover and in respect of which there is no treatment that will improve her current condition. There is likewise no dispute that this injury will severely limit Alta’s life expectancy. Within this context, I am satisfied that the aspect of Alta’s medical condition and prognosis that is, in addition to the other non-medical factors that will inform the court’s best interests decision, central to the court’s determination is the question of whether Alta experiences pain.

79. Having regard to the evidence before the court, on the first question with respect to the issue of pain, I am satisfied that Alta does consistently exhibit movements that, if she is able to experience pain, will cause her pain, in the form of regular spasms in response to handling during care tasks and in response to medical interventions.

80. The clinicians who are involved with the treatment of Alta on a consistent basis (informed by the records kept by the nursing staff who are involved in the treatment of

Alta on a constant basis) are clear that Alta regularly exhibits whole body spasms and shudders in response to contact. This situation is also reflected in the evidence of the Children's Guardian from her experience of sitting with Alta. The experience of the treating clinicians is, as I have set out above, also reflected in the observations made by the experts who have examined Alta for the purposes of these proceedings. Within this context, Dr Ross Russell also considered, having regard to her medical records, that it is "indisputable" that Alta does have episodes of spasm on handling, even if he considered from his very limited examination that they do not occur on every handling.

81. With respect to the latter issue of the constancy of Alta's responses, which forms a central aspect of the parents' case, I accept the expert evidence of Dr Hart that it is the question of whether a *consistent* response to stimuli over an extended period of time is identified in Alta that is key, rather than the question of whether such a response is *constant*. In my judgment this must be the correct analytical approach having regard to the variability inherent in the stimuli applied to Alta by different individuals (as readily demonstrated by the different views expressed as between Dr Ross Russell, who did *not* apply painful stimuli such as supra orbital pressure, and the treating clinicians who have undertaken such testing), the medication being administered to Alta to address her spasms and other symptoms and level of damage sustained by Alta's brain leading to the possibility inconsistent brainstem hosting of response. These factors will, I am satisfied, lead to the likelihood of some instances of lack of response even if, overall, Alta's demonstrates a consistent response over time. In this context, the balance of the clinical and expert medical evidence before the court is that, over an extended period of time, Alta consistently exhibits whole body spasms in response to handling, care giving and treatment.
82. It is correct that the observations of the clinicians, whilst internally consistent and consistent with the experts and the Children's Guardian, are not consistent with parents' and Rabbi Goldberg's observations. However, I am satisfied that I must prefer medical evidence, and that of the Children's Guardian, over that of the parents and Rabbi Goldberg. Whilst there is no question as to the *bona fides* of their evidence, four factors have to be borne in mind when the court considers the weight to be attached to their observations. First, it is not disputed by the parents or Rabbi Goldberg that Alta does sometimes exhibit spasms when handled and when subjected to treatment. Second, in part for reasons that the court is aware but does not need to detail in this judgment, and in part by reason of choice, the parents have had little contact with Alta in hospital. This must necessarily reduce significantly the weight the court can attach to the parents' assertions regarding the nature and pattern of Alta's response to handling, care and treatment. Whilst Rabbi Goldberg visits more often, his interaction with Alta is less comprehensive than that of the treating clinicians and nursing staff. Third, the parents are, inevitably, in these very difficult circumstances subject to the flattering voice of hope. This must also necessarily affect the weight that the court can attach to the parents' perceptions of Alta's presentation. Fourth, neither the parents nor Rabbi Goldberg are medically qualified and necessarily observe Alta's responses from a lay perspective rather than a medical one. In such circumstances, I am satisfied that the evidence of the treating clinicians and experts should attract greater weight on the first question of the extent is Alta exhibits movements that, if she is able to experience pain, will cause her pain.

83. Whilst Alta's parents further rely on Dr Ross Russell's observations of Alta's responses, I am likewise satisfied that the evidence of Dr Ross Russell must attract less weight than the treating clinicians when considering the extent is Alta exhibiting movements that, if she is able to experience pain, will cause her pain. Whilst Dr Ross Russell suggests that they do not occur on every handling, Dr Ross Russell did not examine Alta prior to his first report and his time with Alta ahead of submitting his addendum report was necessarily *far* more limited than that spent with her by the treating clinicians and nursing staff. As I have noted, in any event Dr Ross Russell also considered that, having regard to her medical records, that it is "indisputable" that Alta does have episodes of spasm on handling, care giving and treatment.
84. Finally, in addition to preferring the observations of the treating clinicians over those of the parents and Rabbi Goldberg regarding Alta's responses to handling, care giving and in response to medical interventions for the reasons I have given, I also attach weight to the expert evidence of Dr Hart highlighting the significance of the scans and EEG results for Alta, including the Paediatric Video Ambulatory EEG Report dated 1 April 2020 which records that:
- "...on many occasions throughout the recording, particularly when attended or in relation to tactile and auditory stimulation, child had episodes with stiffening, mouth opening and tremoring associated with staring lasting for many minutes."
85. Satisfied as I am on the balance of probabilities that Alta exhibits whole body spasms on handling, care giving and treatment I am further satisfied the spasms and associated sequelae exhibited by Alta will, if she is able to experience pain, be painful. Each of the treating clinicians, and each of the medical experts, including Dr Ross Russell, gave evidence that the spasms experienced by Alta would ordinarily be painful. The evidence given in this regard likened the pain generated by such consistent whole body spasms to severe muscle cramp.
86. Within the foregoing evidential context, I find as a fact on the balance of probabilities that, over time, Alta consistently exhibits spasms as described by her treating clinicians by way of response to handling, care tasks and treatment which, if she is capable of experience pain, will cause Alta pain. Further, I am likewise satisfied on the balance of probabilities that, whilst a more difficult question for the court to answer, Alta *experiences* pain.
87. With respect to the second question of whether Alta experiences pain, I accept the evidence of Dr Hart and Dr A that the anatomical pathways that mediate the reflexive response pain are, to a greater or lesser extent, intact in Alta. Dr A's detailed evidence in this regard demonstrates to my satisfaction that although both Alta's brain stem and her thalami are damaged they are still partially functional and that therefore critical structures for perception of pain remain present and therefore she can still perceive pain. Dr Hart likewise confirmed, in his capacity as the expert paediatric neurologist in this case, that the scans of Alta's brain indicate that a limited area of her cortex has survived and that the EEG results indicate some degree of activity in Alta's cortex, albeit abnormal in nature. As I have noted, Dr Hart also considered that twitching seen in Alta in association with epilepsy indicated some surviving connections between Alta's cortex and her muscles. Within this context, I again bear in mind the evidence of Dr



Hart highlighting the significance of the scans and EEG results for Alta, including the Paediatric Video Ambulatory EEG Report dated 1 April 2020.

88. Within the foregoing context, I am further satisfied that the evidence before the court demonstrates on the balance of probabilities that Alta remains able generate a reflex to pain, albeit that she lacks the cerebral structures to derive meaning from this or any understanding of the pain. In my judgment, the evidence before the court demonstrates that Alta exhibits consistently a consistent response to the application of painful stimuli. Dr B, who has regular clinical involvement with Alta, was clear that the application of painful stimulus such as nail-bed pressure, supra-orbital pressure or trapezius squeeze, causes Alta to exhibit the whole-body spasms that I have found Alta exhibits and, albeit more inconsistently, causes head movement (slight rotation to the right), mouth-opening and tachypnoea. Within this context Dr Hart, the expert paediatric neurologist instructed in this case, stated that what is seen consistently in respect of Alta is that when a painful stimulus is applied a consistent response results. I accept the evidence of both Dr B and Dr Hart. I am not able to attach significant weight to the opinion of Dr Ross Russell on this issue in circumstances where, by his own admission, his examination of Alta did not include the application of painful stimuli by way of nail bed pressure or supra orbital pressure or otherwise and conceded that his evidence with respect to this issue was “inexpert”.
89. Whilst Ms Butler-Cole and Dr George have urged upon the court reliance on the RCP guidance as demonstrating that the responses seen in Alta are not, in fact, evidence that she experiences pain, I do not find that guidance to be of particular assistance in determining the question of whether, on the balance of probabilities, Alta can experience pain. The RCP guidance is not guidance promulgated with respect to infants, who are both physiologically different to adults and differ in terms of conscious awareness of environment, learning, movement and reflexes. Further, to my reading, the RCP guidelines do not rule out the possibility that reflex responses in a person in PVS can denote the experience of pain. Within this context, I am satisfied that a consensus statement from those specialisms concerned with patients over the age of 16 with PVS or MCS does not greatly assist the court in determining in an individual case the extent to which an infant in Alta’s position experiences pain.
90. Within the foregoing context, I find on the balance of probabilities that Alta is able to experience pain. I am further satisfied on the evidence before the court that, in light of the courts finding that Alta exhibits movements that, if she is able to experience pain, will cause her pain, her experience of pain represents a significant burden to Alta.
91. I accept that the question of whether Alta is able to experience pain as a burden is complicated by the fact that, whilst satisfied that Alta exhibits a response to painful stimuli through intact or partially intact reflexive pathways, we have no means of knowing the exact *nature* of her experience of pain given the catastrophic nature of her brain damage. The difficulty is compounded by the fact that the language that has to be deployed in an attempt accurately to describe Alta’s experience is language that has been, as with all human language, developed to describe conscious experience. We do not have language to describe properly, or perhaps at all, the experience of pain divorced from conscious thought. Within this context, I accept that this issue brings the court close to the boundary between the legal and the metaphysical. That said, I am satisfied that the fact that it is not possible to describe exactly the nature of Alta’s

experience of pain does not prevent the court from finding that, being satisfied that she is able to experience pain, that experience of pain is a significant burden to her.

92. Being satisfied that Alta is able, for the reasons I have described, to experience pain, I am further satisfied that the court can and should proceed on the basis of the general human understanding that pain is a negative experience and that a person who experiences pain bears a burden. Whilst I accept that, ordinarily, this proposition assumes conscious thought as a pre-requisite, I am satisfied on the evidence before the court that this need not inevitably be the case. Even if the pain that I am satisfied Alta responds to is not ‘felt’ by Alta emotionally or understood by her cognitively, in the context of her consistent response to painful stimuli and the nature of pain that is known to be generated by the repeated and consistent responses to handling, care giving and treatment by Alta (namely spasms that are said to be akin to severe muscle cramp) there is no reason to consider that such pain would be experienced by Alta any other way than as a negative experience. Indeed, the experience of pain without the ability to understand it is arguably an even worse predicament than pain accompanied by understanding. On the evidence before the court, the pain experienced by Alta can be associated with any of the handling, care giving and treatment she is subjected to and with the physical conditions from which she may suffer, for example, constipation and from positions that may create pressure points on parts of her body. Within this context, I am reminded of the evidence of Dr A that the statement “It is impossible to know how much she feels” with respect to Alta may be correct but:

“She cannot tell us and this puts even more responsibility on her carers. It is impossible to know how much a new-born feels or how much a profoundly disabled person feels but nonetheless we use all the knowledge available to us to make sure we minimise any suffering they experience...Alta definitely lacks the ability of the higher functions as her brain centres for these higher functions have been destroyed but she feels the pain. She feels pain and is unable to protect herself from it, she is unable to understand why this pain is there, she is dependent on us to help her.”

93. With respect to the court’s findings regarding Alta’s prognosis, it is plain from the evidence the court has heard that it is difficult to arrive at a definitive assessment of Alta’s life expectancy. As Dr Samuels observed, having regard to the complexity of Alta’s condition and to her vulnerability, the only real certainty with respect to her life expectancy is uncertainty. However, I am satisfied that it is appropriate for the court to take account of the fact that whilst it is possible that Alta could succumb quickly if she develops an infection, on the upper estimates before the court it is possible that Alta may, subject to the continuation of intensive care and in all likelihood an escalation in that level of care, remain alive for two or more years. Within this context, I am satisfied on the evidence before the court that Alta has no prospect of recovery or improvement given the severe nature of her brain injury. The evidence before the court demonstrates that Alta will remain ventilator dependent and without meaningful awareness of her surroundings.
94. As I have observed above, the question of prognosis is not simply one of life expectancy for the purposes of the application of the best interests test. On the evidence before the court, I am further satisfied that over the remainder of her short life it is more probable than not that Alta’s condition will significantly deteriorate. Whilst Ms Butler-Cole succeeded in demonstrating in cross-examination that predicted deteriorations in a

number of areas have not yet come to pass, I accept the expert evidence of Dr Hart that Alta's symptoms are going to worsen, and she will accumulate further comorbidities that will increase the burden of pain that I am satisfied that she is bearing, including worsening dystonia and spasticity with associated pain, hip dislocation and pain, scoliosis, which may be painful, pressure sores corneal abrasions and ulcers and urinary tract infections.

### *Best Interests*

95. The starting point in the analysis of Alta's best interests is to consider the matter from the assumed point of view of Alta. As I have noted elsewhere, there are inherent and obvious difficulties in a judge seeking to place him or herself in the shoes of a two year old child. In undertaking this difficult exercise I am not able, in circumstances where Alta suffered a brain injury that left her with no ability to learn about the world around her before she was able to understand anything of religion and culture into which she was born, to accept the submission that the assessment of Alta's perspective on this matter should start by assuming, without more, that Alta would share the values of her parents, of her brother, and of her wider family and community. I accept that a child's attitude may be, and indeed often is influenced by the views, beliefs and guidance of his or her parents. But the child remains an individual in his or her own right. In some cases, of which *Raqeeb* was an example, there may be evidence that will allow the court to make an informed judgment as to the extent to which a child shares in their parents' values and the values of their community and factor that into the overall evaluation of best interests. That is not the case here. Alta is not of an age, nor in a condition to have knowledge of and to adopt her parents' values, from which she could extrapolate a position on the complex issues that arise in this case.
96. In these circumstances, and absent *any* evidence to assist the court in determining the extent to which Alta would adopt wholesale the views of her parents, I am satisfied that the furthest the court can safely go in seeking to place itself in Alta's shoes is to acknowledge that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents. Within this context, I have held in mind at all times the strict religious credo that the parents adopt and the tenets of that credo as they relate to the withdrawal of life sustaining treatment. I have also borne in mind that a person may wish to continue to receive treatment notwithstanding the presence of profound disability and that the court cannot simply assume that a profoundly disabled child will not wish to lead a life affected by disability. However, against these matters, I am satisfied that I must also have regard to the fact that Alta's likely attitude to treatment would be influenced by the fact that the prospect facing her if treatment is maintained is one of continued medical intervention that will do not more than maintain her in a moribund state with no awareness, with no prospect of improvement or recovery, the certainty of further physical deterioration and, as I have found above, in a situation of consistent pain. Within this context, in discharging the difficult task of asking myself what Alta's attitude to continued life sustaining treatment would be likely to be, I am satisfied that, in circumstances where she has not developed any understanding of the faith into which she was born, and giving due weight to the fact that a child's attitude may be, and often is influenced by the views, beliefs and guidance of his or her parents, it is more likely than not that Alta's point of view would be that continued life sustaining treatment would not be acceptable to her.

97. In undertaking the best interests evaluation, I have placed considerable weight on the fact that there is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in Alta, giving the fullest possible weight to humankind's collective desire to survive. The sanctity of life is a fundamental, indeed sacred, principle from which there flows a strong presumption in favour of a course of action that will prolong life. Whilst, understandably, the parents seek to locate the principle of the sanctity of life within the strict religious paradigm to which they each hold, the sanctity of life is recognised in both the religious and the secular spheres. Further, the sanctity of life is of equal application to everyone. Alta is profoundly disabled but a life of disability is of equal value to all other lives. Notwithstanding Alta's parlous position, her life is valuable in itself and for the manner in which it adds, during her brief time in the world, to the collective human experience from which we can all learn. Alta's life has value for her, to her sibling and, without question, has value to her parents. Alta's life also has inherent value. Within this context, in reaching a decision as to Alta's best interests I acknowledge the strong presumption in favour of continuing the treatment that will prolong Alta's life.
98. However, the sanctity of Alta's life is not, within the context of the secular laws that this court must apply, absolute. It may, on the facts of an individual case, give way to countervailing factors. In short, the presumption in favour of taking all steps to preserve life, whilst strong, is also rebuttable. That this is so recognises that life cannot be, and indeed should not be preserved at all costs.
99. In Alta's case I am satisfied that the fact that Alta is in consistent pain acts as very heavy counter-weight to the presumption. I have of course cautioned myself that, as was made clear in *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33, pain is but one factor to be placed in the best interests balance and, in particular, that intolerability is not a quasi-statutory yardstick when determining best interests. However, having regard to the findings I have made in this case with respect to Alta's experience of pain, associated with any of the handling, care giving and treatment and with physical conditions from which she suffers, I am satisfied that that experience is a very weighty factor in the best interests analysis of the court. The weight to be attached to this factor is further enhanced in circumstances where it is possible that with intensive care Alta will survive for a number of years but will, as I have found, accumulate in that time further comorbidities that will increase the burden of pain that I am satisfied that she is bearing, including worsening dystonia and spasticity with associated pain, hip dislocation and pain, scoliosis, which may be painful, pressure sores, corneal abrasions and ulcers, and urinary tract infections.
100. In addition, and turning to consideration of the nature of the medical treatment in question for Alta, I have attached significant weight in the best interests analysis to the fact that the treatment that the parents contend should continue, namely mechanical ventilation, tube feeding and the all of the associated ancillary treatments will itself, within the context of the findings I have made regarding Alta's experience of pain, continue to place a significant burden on her without any prospect of improving her medical condition. Within this context, in evaluating Alta's best interests the court must factor into that analysis the fact that the burdens of life sustaining treatment for Alta, as particularised in the statements of Dr B, outweigh by a significant margin any benefits beyond that of maintaining fidelity to the principle of the sanctity of life. Alta

will derive no benefit from the medical treatment being administered such that she will continue to suffer from profound cognitive impairment that will not change.

101. With regret, I am satisfied that I must reach the same conclusion with respect to the nature of the treatment regime that comprises the parents' primary case. Namely, the transfer of Alta to Israel for continued life sustaining treatment at an Israeli medical institution. The evaluation of this option has been significantly hampered by a paucity of detailed information regarding the option that is advanced by the parents as their primary case. Whilst the court has email confirmation that two institutions in Israel would be prepared to accept Alta as a patient, there are no details of the treatment regime that would be adopted, no explanation of why Alta would be required to be admitted first to one hospital and then moved again to a second hospital. The Israeli clinicians have not been available for discussions with Alta's treating team in this jurisdiction and, accordingly, there has been no liaison with the clinicians who have a detailed knowledge of Alta's current medical needs. In this context, the court has no information regarding the basis on which the Israeli doctors who indicate they will accept Alta for treatment say that that course is in Alta's best interests. This is, I am satisfied, a wholly insufficient basis on which to conclude that transfer to Israel for continued life sustaining treatment would be in Alta's best interests.
102. In any event, I am satisfied that even were there a detailed proposal for transfer available to the court, having regard to the court's findings with respect to Alta's experience of pain and to the court's findings as to her prognosis, it cannot be said to be in Alta's best interests to be transferred to Israel for life sustaining treatment to continue. To take that course of action would, on the evidence of the treating clinicians and each of the experts instructed in this case, be to expose Alta to further pain and discomfort during the course of transfer for no medical benefit in circumstances where all parties accept that the treatment options now available for Alta provide no prospect of recovery.
103. Within this context, and having regard to the particular facts of Alta's case, I am satisfied that the court must also take into account the fact that, added to pain and burden of treatment in both the contexts I have set out above when examining the issue of the proposed medical treatment, Alta has and will continue to have minimal or no awareness of her family and social relationships, minimal or no ability to respond to external stimuli so as to take comfort or enjoyment from those who love her or the world around her and engage in the enlargement of knowledge of her world. Further, whilst I accept the cautionary observations of Poole J in *Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight* regarding the concept of dignity as a factor to be considered in cases of this nature, in the context of the concept of human dignity, although difficult to define, I am satisfied that the court must also take into account the fact that continuing life sustaining treatment will confine Alta to being kept alive for the remainder of her life in a hospital room without windows, her life sustained by machines in a world she cannot meaningfully perceive or connect with.
104. With respect to the views expressed in this case by Alta's treating clinicians and the medical experts instructed to assist the court, it is well established that I am not bound to follow the clinical assessment of the doctors but must form my own view as to the child's best interests. On the particular facts of this case however, and within the context of the findings I have made as set out above, I consider that I am bound to give significant weight to the fact that both the treating clinicians and each of the experts instructed in this case, including Dr Ross Russell, the paediatrician instructed on behalf

of the parents, are agreed in their view that it is no longer in Alta's medical best interests to receive life sustaining treatment.

105. There is no requirement for the court to evaluate the reasonableness of the parents' views before it embarks upon deciding what, objectively, is in the child's best interests. Further, whilst the views of the parents may have particular value in circumstances where they know well their own child, that proposition comes under some strain in this case in circumstances where the parents have, as I have described, had little contact with Alta. The court must also be mindful that the views of the parents may, understandably, be coloured by emotion. All that said, I am satisfied that in this case it is important to examine the views of the parents, particularly in circumstances where those views crystallise around their strongly held religious convictions and the weight the parents contend the court should place on that factor in reaching its best interests decision.
106. In this case the parents' views are informed by their strong religious belief as Ultra-Orthodox Jews. Within this context, I have considered very carefully their evidence on this subject and the extremely helpful evidence of Rabbi Goldberg in seeking to understand the religious tenets that the parents contend impact upon this case. In some respects, it might be said that the approach articulated by certain rabbinical scholars is not so different to the secular task assigned to the court, namely, and to paraphrase Rabbi Goldberg's formulation, the question is how one is to balance the presumption in favour of preserving life with the need to alleviate suffering. However, and as would be the position were the court concerned with the religious principles observed by Christianity, Islam, Hinduism, Buddhism or any of the world's established religions, it is not religious law that governs the decision in this case but the secular law of this jurisdiction. Within this context, and self-evidently, the analysis the court must undertake is much wider in its ambit than the rabbinical analysis that informs the position that is taken by the parents in this case.
107. Whilst the rabbinical analysis may rest on the question of the extent of Alta's suffering (and acknowledging that that analysis is more or less strict depending on the strand of rabbinical teaching that is being considered), the question for the court is what outcome is in Alta's best interests taking into account *all* relevant factors, including the pain the court has found that Alta consistently experiences. Accordingly, the spiritual considerations that the parents urge upon the court fall to be considered alongside the very worldly issue of the consistent pain that the court is satisfied that Alta experiences (which, according to certain rabbinical schools, is an approach that Jewish law also recognises) and the additional burdens on her of treatment and her condition. Within this context, it is further important to note that, insofar as the parents Art 9 right to freedom of thought, conscience and religion is engaged in this case and must be accorded weight (in respect of which I did not hear detailed argument), the right to freedom of thought, conscience and religion may be circumscribed where this conflicts with the subject child's best interests. Within this context, as I have noted in other cases, in *Prince v Massachusetts* (1944) 321 US 158 the US Supreme Court held that parents' rights to manifest their religion are necessarily circumscribed by the interests of the child in that:

“... neither rights of religion nor rights of parenthood are beyond limitation. Acting to guard the general interest in youth's well-being, the state as *parens patriae* may restrict the parent's control by requiring school attendance,

regulating or prohibiting the child's labor [*sic*] and in many other ways. Its authority is not nullified merely because the parent grounds his claim to control the child's course of conduct on religion or conscience. Thus, he cannot claim freedom from compulsory vaccination for the child more than for himself on religious grounds. The right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death ... [T]he state has a wide range of power for limiting parental freedom and authority in things affecting the child's welfare; and that this includes, to some extent, matters of conscience and religious conviction ..."

108. Within this context, whilst I have considered carefully, and accorded respect to, the views of the parents and the evidence of Rabbi Goldberg, I am not satisfied that the strict religious principles to which they hold outweigh the other, compelling, factors that point in the opposite direction in the best interests analysis.
109. Within the foregoing context, I am satisfied that the burden of Alta's underlying condition, generating as it does an experience of consistent pain for Alta and leaving her as it does in a state of perpetual darkness and silence, acts to overcome the benefits in sustaining her life. In the circumstances, and having examined Alta's best interests from a broad perspective, encompassing medical, emotional, sensory and instinctive considerations, and having paid due regard to the fundamental, but not immutable principle of the sanctity of life, as well as the parents' deeply held religious convictions, it is with deep regret that I am satisfied that it is not in Alta's best interests for life sustaining medical treatment to be continued and in her best interests for that treatment now to be withdrawn and to be moved to a palliative care regime.
110. With equal regret, having regard to the secondary case advanced by the parents, I am not persuaded that it is in Alta's best interests for her to be transferred to Israel for the withdrawal of medical treatment to take place.
111. First, and again having regard to the court's findings with respect to Alta's experience of pain and to the court's findings as to her prognosis, it cannot be said to be in Alta's best interests to be transferred to Israel in circumstances where to take that course of action would, on the evidence of the treating clinicians and each of the experts instructed in this case, be to expose Alta to further pain and discomfort during the course of transfer for no *medical* benefit. Whilst I accept that transferring Alta to Israel for the withdrawal of life sustaining would mean that her last days or weeks would be spent with her family who would have support for themselves and Alta's brother, that her death and burial would be able to occur in accordance with the religious beliefs of the family, including being buried with wider family including her paternal great-grandmother and that her grave would be in Holy Land, and her parents would be able to visit it to remember her and to pray, I am not satisfied that these necessarily adult concerns can outweigh the additional burden of pain that would be placed on Alta by a transfer, particular in circumstances where it is conceded that it is possible to transfer Alta for burial in Israel after her death. Likewise, whilst I accept that, from the perspective of Jewish law, there would be spiritual benefits to Alta in ending her life in Israel, as helpfully articulated to the court by Rabbi Goldberg, I am not satisfied that those spiritual benefits are sufficient to outweigh the additional burden of pain that would be placed on Alta by a transfer, again particularly in circumstances where, whilst

not spiritually optimal, it is possible to transfer Alta for burial in Israel following her death in this jurisdiction.

112. Second, and more fundamentally, this court having concluded that withdrawal of life sustaining treatment is in Alta's best interests, there is no evidence that that course of action would be endorsed following the transfer of Alta to the jurisdiction of Israel. At the very least, Ms Butler-Cole and Dr George concede the decision of this court would not be directly enforceable in Israel and that an order of the Israeli court authorising withdrawal of treatment would be required. This court has not had the benefit of expert evidence on Israeli law to assist it in evaluating the likelihood of such an order being granted. However, the letter from the Chief Rabbi of Israel suggests that parents have rights under Israeli legislation that may mean that were they to seek a different decision in Israel to the one reached by the court in the jurisdiction in which Alta is habitually resident, such a decision may be granted. This is particularly the case where, as I have observed, there are plainly different schools of rabbinical thought regarding the permissibility of withdrawing life sustaining treatment. For example, and accepting I did not hear from him, Rabbi Mansour gave a more categorical view to a meeting on 9 December 2020 to the effect that the Jewish faith does *not* believe in shortening life because of pain. Whilst Ms Butler-Cole and Dr George urge upon the court a delay in the implementation of its decision whilst these matters are clarified and an application made to the Israeli court, I am satisfied that such a delay would be inimical to Alta's best interests in circumstances where she is, as I have found, the subject of consistent pain.
113. Third, I am satisfied that it would, from a human perspective, be unfair to put temptation in the way of the parents and their family. Both parents gave clear, spontaneous evidence to the court that they would respect the court's decision even if it is not what they themselves think is best for their daughter and would accept the withdrawal of life sustaining treatment in Israel. I have absolutely no doubt that each parent's statement to me that they would abide by the decision of the court was made in good faith and that, at the time those statements were made, each parent intended fully to honour them. However, the formal context of the courtroom is very different to that provided by the embrace of close family and friends. It would not be surprising at all if, having arrived in Israel for the purposes of the withdrawal of life sustaining treatment, the decision of an English judge now over 2000 miles distant were to be overborne by the siren call of friends and family deeply connected to the religious traditions that are a way of life for the parents and their family.
114. In the circumstances, I regret that I likewise cannot accede to the parents' secondary case, satisfied as I am that it would not be in Alta's best interests for the court to do so.

## CONCLUSION

115. As I observed in *Raqeeb*, the dilemma presented by cases concerning the withdrawal of life sustaining treatment from a child rests on the fact that such cases address what many see as an appalling present, but a present that for many also remains sanctified morally or as an article of religious faith because life subsists. The report of the Children's Guardian relates that the name Alta can be translated from the Yiddish אַלטע to mean "old, to have long life". I understand that Alta is a name sometimes given to an ailing new-born child by Jewish parents in an effort to confuse the Angel of Death, in the hope



that he will look elsewhere, although whether that was the case in relation to Alta I do not know.

116. Within this context, it is with profound regret that I must conclude on the evidence before the court that it is in Alta's best interests for the treatment that is currently sustaining her precious life now to be withdrawn. The parents cannot be criticised for having reached a different decision informed by the religious laws that govern their way of life. But applying the secular legal principles that I must, and according due respect to the deeply held religious convictions of the parents, I cannot agree with their assessment and am required to act accordingly. As Waite LJ made clear in *Re T (a minor)(wardship: medical treatment)* [1997] 1 All ER 906 at 916-917:

“The starting point, and the finishing point too, must always be the judge's own independent assessment on the balance of advantage or disadvantage of the particular medical step under consideration”.

117. In concluding this judgment, it is also important to mark the dedication and care of the medical team who have treated Alta with the utmost care and dedication since her birth and during a period of unprecedented pressure and difficulty within the NHS. The Children's Guardian expresses it in eloquent and moving terms:

“I was incredibly moved by not only the skilled care of the medical team but also by the strength of love and compassion with which they cared for Alta. The first nurse I met was young and engaging. She had expert knowledge of Alta's needs and was to spend her entire twelve-hour shift at her bedside. She spoke to Alta before she did any interventions, used terms of endearment such as ‘gorgeous girl’ and moved her with extreme care. She gave her a bed bath and changed her outfit. She then sponge-washed her hair, patted it dry and then put it in two plaits with clips with tiny bows on. Despite knowing that Alta has no awareness of such, the care and consideration she and the other staff I met gave Alta was obvious... I asked the nurses what it felt like to care for her and all responded with the utmost respect, impressive medical knowledge but with a deep sense of sadness that the care they give, from a nursing perspective but also on a human level, only ever causes her pain. One nurse (several years experienced on paediatric intensive care) said to me ‘I go home and cry about Alta...I came into nursing to make people better, more comfortable and we cannot do that for her’.”

118. For all the reasons I have given, I make a declaration pursuant to the inherent jurisdiction of the High Court that it is not in the best interests of Alta for life-sustaining medical treatment to be continued, and that it is in her best interests for a palliative care regime to be implemented. Whilst it is important now to implement the judgment of the court expeditiously in light of the findings I have made with respect to pain and suffering, a little time will need to be given to allow the parents to come to terms with the decision of the court in order that Alta, I hope, has the benefit of their input and presence at the end of her life. Further, if it is to be the case that Alta is to be taken to Israel for burial following her death then, accepting the uncertainties as to the period of survival following the withdrawal of treatment, careful co-ordination of those arrangements with the point at which life sustaining treatment is withdrawn will need to be made. I am satisfied that that planning should form part of the overall plan that governs the withdrawal of treatment.

119. That, with immense sadness, is my judgment.