Neutral Citation Number: [2021] EWHC 2664 (Fam)

Case No: MA20P02742

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Manchester Civil Justice Centre
1 Bridge Street West
Manchester
M60 9DJ

Date: 06/10/2021

Before:

THE HONOURABLE MR JUSTICE MACDONALD

- -

Between:

Manchester University NHS Foundation Trust	**Applicant**
- and -	
Alta Fixsler (By Her Children's Guardian)	**First Respondent**
-and-	
Chaya Fixsler	**Second Respondent**
-and-	
Abraham Fixsler	**Third Respondent**

- -

Ms Helen Mulholland (instructed by **Weightmans LLP**) for the **Applicant**
Ms Fiona Holloran (instructed by **McAllister Family Law**) for the **First Respondent**
Mr Jason Coppel QC and Mr Bruno Quintavalle (instructed by **TKD Solicitors**) for the **Second and Third Respondents**

Hearing dates: 1 October 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 12 noon on 6 October 2021.

Mr Justice MacDonald:

INTRODUCTION

1. In this matter, I am once again concerned with the welfare of Alta Fixsler. Alta was born on 23 December 2018 and is now 2 years and 9 months old.

2. The application that is before the court remains that 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, Faye Robertson, by Ms Fiona Holloran of counsel. Alta's parents, Chaya Fixsler and Abraham Fixsler, are now represented by a third legal team, Mr Jason Coppel of Queen's Counsel and Mr Bruno Quintavalle of counsel appearing on their behalf at this hearing. The parents are Chassidic Practising Jews and Israeli citizens. The father also has US citizenship.

3. On 18 December 2020, the Trust made an application for 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, and for 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) of the Children Act 1989) determining that life-sustaining medical treatment should cease to be provided and a palliative care regime implemented instead. Those applications were supported by the Children's Guardian.

4. The parents opposed the applications brought by the NHS Trust and instead sought 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 concluded that it was no longer in Alta's best interests for life sustaining treatment to be maintained, for that step to be taken in Israel.

5. On 28 May 2021, I gave judgment granting the Trust's application for a declaration under the inherent jurisdiction of the High Court and declared 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. Following a hearing on 23 June 2021, on 9 July 2021 the Court of Appeal dismissed the parents' appeal against the order of this court. On 14 July 2021 the Court of Appeal refused the parents permission to appeal to the Supreme Court and on 27 July 2021 the Supreme Court refused the parents further application for permission to appeal. On 1 August 2021 the European Court of Human Rights declared the parents' complaint to that court inadmissible, bringing to an end the avenues of appeal available to the parents.

6. The matter now returns to court in circumstances where a further dispute has arisen between the parties. That issue is the *location* at which Alta's life support should be withdrawn by way of extubation, although, as is their right, the parents continue to believe that it is *fundamentally* wrong to withdraw Alta's life-sustaining treatment and that to do so constitutes a grave sin against God. The parents contend however, that if that step must be taken it is a step that should be taken at the family home (although, for reasons I will come to, the property they propose is not, in fact, the family home). The Trust contend that the step should be taken either at the PICU where Alta is being treated or at an identified children's hospice. The Children's Guardian supports the

position taken by the Trust. At this hearing I have heard evidence from Dr B, the consultant paediatric intensivist responsible for Alta's care. The parents decided not to give oral evidence but the court has before it detailed statements provided by the father on behalf of both parents.

7. A mediation took place on 17 September 2021 between the parents and the Trust. That mediation failed to resolve any of the issues that now fall to be determined by the court. Indeed, such is the distance between the parents and the Trust that it was apparent at this hearing that there is now even a dispute as to what occurred on 17 September 2021. This hearing has been arranged so as to avoid the Jewish feast days that occur in September, in order to ensure that the hearing did not take place on a day when Orthodox Jews are prohibited from performing any work or on a day when, whilst not prohibited, Orthodox Jews are expected to avoid work.

BACKGROUND AND EVIDENCE

8. The detailed background to this tragic case is set out in my first judgment, published as *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 1426 (Fam). This judgment should be read with that one.

9. As set out in my first judgment in this matter, 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 has never been 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 where she is in receipt of intensive life sustaining treatment, including intubation and mechanical ventilation.

10. Within the context of that tragic history, having heard detailed and comprehensive expert medical evidence, evidence from Alta's treating clinicians and evidence from the parents and their Rabbi, and applying the legal principles that pertain in this jurisdiction in cases of this nature, I made the following findings of fact based on the evidence before the court:

    i) Alta has sustained a catastrophic brain injury in the form of a severe hypoxic-ischaemic brain injury during her premature birth.

    ii) Alta has no prospect of recovery or improvement given the severe nature of her brain injury. Alta will remain ventilator dependent and without meaningful awareness of her surroundings.

    iii) Alta's brain injury severely limits Alta's life expectancy. 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.

    iv) Alta consistently exhibits 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.

v) Alta remains able to generate a reflex to pain, albeit that she lacks the cerebral structures to derive meaning from this or any understanding of the pain, and exhibits a consistent response to the application of painful stimuli.

vi) On the balance of probabilities, Alta experiences pain and her experience of pain represents a significant burden to Alta.

vii) 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.

viii) It is more probable than not that Alta's condition will significantly deteriorate. Alta's symptoms will worsen, and she will accumulate further comorbidities that will increase the burden of pain 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.

11. With respect to the role of Alta's wishes and feelings in the best interests evaluation, in my first judgment I concluded as follows at [95]:

> "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."

12. Within the context of the foregoing findings and conclusions, and for the detailed reasons set out in my first judgment, I determined that it was 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.

13. Following the handing down of judgment, the parties engaged in a period of negotiation regarding the precise terms of the order consequent upon the decision of the court. The order agreed between the parties, and approved by the court in light of the decision I have summarised above, provided as follows:

"**IT IS DECLARED THAT:**

1. By reason of her age and minority, Alta Fixsler ('the Child') lacks competence and capacity to give her consent to medical treatment.

2. It is not in the Child's best interests for life-sustaining treatment, including mechanical ventilation, to be continued. It is in her best interests and lawful that she should be moved to a palliative care pathway such that:

   a. Mechanical ventilation should be withdrawn; and

   b. There shall be clearly defined limits on the treatment to be provided to her after ventilation is withdrawn; and

   c. The withdrawal of mechanical ventilation shall take place in accordance with the pathway at Appendix 1 to this Order.

IT IS ORDERED THAT:

1. The Applicant and/or the doctors having responsibility for the treatment of the Child shall be at liberty to treat her in accordance with their clinical discretion, subject to the timescales referred to in the appendix, including any decision they make as to removal of ventilatory support.

2. The Applicant and/or doctors and nurses treating her shall generally provide such treatment and nursing and palliative care as may be appropriate to ensure that she suffers the least pain and distress.

3. Any witness statements and reports filed in these proceedings and any Court Orders made in the course of these proceedings shall be placed in the Child's medical records.

4. If any issue arises in respect of withdrawal of life-sustaining treatment including ventilatory support, the parties shall have permission to apply to Court for further directions. Such applications should be heard before Mr Justice MacDonald if he is available.

5. The Second and Third Respondents are refused permission to appeal.

6. Permission to the parents to disclose a copy of this order, its appendix, and the palliative care pathway document to solicitors in Israel and hospitals in Israel in connection with their (renewed) application for permission to appeal.

7. There is no order as to costs."

14. The appendix referred to in paragraph 2c of my order of 28 May 2021 further provided, *inter alia*, as follows:

"2. Withdrawal shall take place:

a. Either at the hospital or at a hospice or at the First Respondent's home according to:

i. the Second and Third Respondents preference; and

ii. whether withdrawal at a particular location can be arranged."

15. As I have noted, the parents appealed the order of this court to the Court of Appeal. On 23 June 2021 the Court of Appeal dismissed the parents' appeal (see *Fixsler v Manchester University Foundation NHS Trust* [2021] EWCA Civ 1018). With respect to this court's findings regarding the burden of pain on Alta, the Court of Appeal held as follows:

> "[61] Mr Simblet recognised that every advocate faces a significant challenge in seeking to persuade this Court to overturn a finding of fact made by a judge at first instance. In this case, with regard to the judge's findings about pain, Mr Simblet has fallen well short of meeting that challenge. The judge was presented with extensive and detailed evidence from the treating clinicians and independent experts about the pain that the child was suffering. He considered that evidence with conspicuous care and in meticulous detail. His finding that Alta suffered pain in response to particular touches or stimuli was fully supported by the evidence. Having read that evidence, I am satisfied that the judge's finding that the child suffers "consistent" pain is a fair description. The pain is not constant but it occurs regularly, although not invariably, when she is subjected to certain stimuli. There is no prospect of an appellate court interfering with his findings about the causes of or degree of pain that Alta is suffering.
>
> [62] The judge rightly regarded the pain that the child is suffering, and will continue to suffer (possibly to a greater degree), as a very important factor in the welfare analysis. I do not agree with Mr Simblet's submission that the strong presumption in favour of preserving life can only be outweighed by "particularly cogent evidence" as to the "unbearable" nature of the pain the child suffering. I do not accept the submission that the evidence of pain in this connection has to be this "particularly" cogent. Evidence of pain in a patient with the degree of disability from which Alta suffers is often extremely difficult to obtain. Although the Somatosensory Evoked Potentials test was not carried out, the evidence put before the judge was detailed and coherent and plainly sufficient to support his findings.
>
> [63] Furthermore, I do not accept that pain has to be "unbearable" or "intolerable" for an application to withdraw treatment from a child to succeed. What is required is a balancing of all factors relevant to the child's welfare. Any significant degree of pain will be a factor to be weighed in the balance. Manifestly, the greater the likely degree and intensity of pain, the greater the weight it will be likely to carry."

16. Further, with respect to the conclusion of this court that it could not be assumed that Alta would share the views of her parents, Lord Justice Baker concluded as follows at [86]:

> "I agree with MacDonald J's observation (at paragraph 123) in Raqeeb that:
>
> > '[given] the fact of evolving capacity, the sophistication of the values and beliefs of those children vary widely in accordance with their age and understanding, the concepts of thought, conscience and religion implying a developing capacity to understand, appreciate and engage rationally with competing ideas and beliefs and, ultimately, the fully formed capacity to exercise choice in respect of those ideas and beliefs.'
>
> In my judgment, the judge was entitled in the present case to refuse to assume that Alta would share the values of her family in circumstances where she never has had, nor ever will have, the ability to understand anything of the original culture into which she was born. As he said (at paragraph 95 of the judgment in this case) 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.'
>
> In the case of a very young child in Alta's condition, the element of substituted judgment in the best interests decision is very limited and in this case is certainly outweighed by other factors, including in particular the fact that she is suffering consistent pain."

17. The parents sought permission to appeal to the United Kingdom Supreme Court but were refused permission by the Court of Appeal on 14 July 2021 and by the Supreme Court on 27 July 2021. As I have noted, the appeals process was exhausted on 1 August 2021 when the European Court of Human Rights declared inadmissible the parents' complaint that the decision of this court breached their human rights under the ECHR.

18. During the course of the appellate process the parents were not, understandably, willing to discuss the issue of the withdrawal of Alta's treatment. Following the appellate process reaching its conclusion, a meeting took place between the parents and clinicians on 9 August 2021, at which the parents indicated they needed time to consider the options and to reflect. In his first statement, the father confirms that this meeting was cordial and that the parents felt that the Trust were willing to explore all of the options available to the family with respect to the withdrawal of Alta's life-sustaining treatment.

19. In his first statement for this hearing, Dr B indicates that at the meeting on 9 August 2021 it was agreed that the Trust would evaluate the feasibility of withdrawal of mechanical ventilation at the family home and a risk assessment of the home would be undertaken jointly between the lead community nurse and a PCC Transport Consultant. It was further agreed that the Family Liaison and Bereavement Support Sister would explore the parents' training needs, required to facilitate a withdrawal of mechanical ventilation at home, with the PCC's Education Team. The parents further agreed to make contact with an identified children's hospice to arrange a visit.

20. Two days later, on 11 August 2021, the parents indicated through their solicitors that they were no longer willing to communicate with Alta's treating doctors concerning the introduction of palliative care. The email from Moore Barlow Solicitors (who were acting for the parents at the time) stated that "all communication must be through the solicitors" and asked the Trust to confirm that "there will be no direct contact with our clients". On 11 August 2021 the parents visited the hospice and discussed the family's requirements should Alta be admitted to that venue. In the Position Statement prepared by Mr Coppel and Mr Quintavalle on behalf of the parents it is made clear that the parents were very happy with the assistance they received from the hospice.

21. Within the foregoing context, the parents' home was assessed on 11 August 2021. As I have alluded to, there has been a question mark, raised initially by the Children's Guardian, over whether the property that has been assessed is in fact the family home, or a different property. In his Position Statement for the hearing before this court on 9 September 2021, Mr Quintavalle confirmed that the parents have acquired a ground floor flat to meet a concern regarding access for Alta, and the medical equipment she requires, to the family home. Whilst the pictures available to the court show a bare property, Mr Coppel informed the court that the parents assert that they are now living at that rented property.

22. In a report dated 13 August 2021, having considered the practicalities of withdrawal of treatment at the rented property, the Trust determined that withdrawal at that property was not a medically viable option by reason of the fact that the property was inaccessible to a PCC transport trolley and that withdrawal of mechanical ventilation at that location could not be undertaken without an unacceptable level of risk of adverse outcomes for Alta, the transport team, and their equipment. The property was confirmed to meet the nursing criteria, subject to the fitting of a smoke alarm, which has now been done. In the foregoing context, the Trust's solicitor wrote to the parents' solicitors on 13 August 2021 outlining that Alta's treating doctors considered that the appropriate locations for withdrawal of treatment were in a children's hospice or the PICU and asked the family to indicate its preference by 4pm on 18 August 2021.

23. On 18 August 2021, the Trust was provided by the solicitors for the parents with an assessment from Hatzola Manchester Ambulance Services, which asserted that that organisation would have no issue entering the rented property with a bariatric stretcher. Against this, Dr B contends in his statement that Hatzola does not have experience in transporting critically ill, mechanically ventilated children and is not familiar with a PCC transport trolley and the equipment associated with it, which includes a mechanical ventilator, monitors, infusion pumps and other equipment. Dr B asserts that an intubated child must be transferred by a dedicated Paediatric Critical Care transport team with appropriately trained doctors, nurses and paramedics, using a standard and not inconsiderable set of equipment. In his first statement, Dr B further contends that Hatzola does not have the experience or knowledge necessary to make a valid accessibility assessment of the property proposed by the parents within the foregoing context. Whilst Hatzola acknowledges, in a further response dated 24 August 2021, that "a level 3 (Advanced Critical Care) transfer due to the patient requiring continuous ventilation, this would normally indicate using the NWTS Service", Hatzola contends that it is able meet Alta's needs with respect to

transportation in this case on the basis of the "rare exception" represented by a patient requiring palliative care. By way of reply to that assertion, Dr B contends as follows in his fifth statement:

> "[13] I have considered the contents of the letter dated 24 August 2021 (only provided to the Trust when exhibited to Mr Fixsler's statement of 9 September 2021) from Tom Goodwin, Clinical Lead – Advanced Paramedic, Hatzola Manchester Ambulance Service. I can confirm that there are no circumstances where a critically ill, mechanically ventilated, physiologically unstable child, such as Alta, would be transferred from our PICU to any destination by a service such as Hatzola Manchester. Mr Goodwin appears to suggest that the Hatzola service should undertake any transfer of Alta independently, citing NWTS documentation which states that a 'rare exception' to NWTS/PICU teams undertaking the transfer of ventilated children 'may be palliative care'. In Alta's case, there is no reason at all to compromise on the expert-level transport care afforded by a NWTS/PICU transport team, and Alta's degree of physiological instability would make a non-specialist transfer highly inappropriate."

24. A second assessment of the rented property took place on 13 September 2021. The Trust contend that there were difficulties in arranging this visit and that it had to take place without the parents being present and that the Trust was only permitted to examine the exterior of the property. The parents assert that the parents were present and gave assistance to Dr D. It was confirmed that the doors to the property were now wide enough to admit a stretcher, although the ramps put in place remained untested.

25. With respect to the question of equipping the parents with the skills required to meet Alta's needs following extubation, if that were to take place at the property rented by the parents, in his statement Dr B sets out the context of the training requirement as follows:

> "[13] As I have previously described, whilst giving oral evidence, Community Paediatric Nursing teams are unable to provide 24-hour support to families in this position, so parents must be able to provide safe nursing care and interventions independently. The skills required include management of Alta's tracheostomy, safe oxygen administration, feed administration and medication management. This adds a considerable burden to parents and these factors explain why withdrawal of mechanical ventilation at home is so rarely undertaken; only once or twice each year."

26. Within this context, on 12 August 2021 the Trust's education team informed Dr B that it would take several weeks to train the parents with the skills required to mange Alta in a domestic environment, assuming the parents were to attend at Alta's bedside each day to develop the necessary competencies. The parents have received some tracheostomy training but the Trust contends that has not been practiced and maintained. Dr B further asserts that the parental delivery of complex healthcare interventions requires commitment to an extended, co-operative working relationship with the PICU nursing staff, PICU clinicians and experts from other elements of the multi-disciplinary team, which does not exist in this case. For their part, the parents contend that they are willing to undergo the necessary training but that the Trust has refused to provide the same. This assertion is, in turn, flatly refuted by the Trust.

27. Within the foregoing context, I note the following entry from the nursing records provided by the parents dated 15 August 2021, some twelve days before the parents' solicitors wrote to the Trust on 27 August 2021 accusing the Trust of denying the parents "opportunity to progress tracheotomy training":

> "I had asked Mum and Dad if they were aware of the tracheostomy competency packs, as would be able to change Alta's tapes and go through the first part of the competency pack with them. Dad explained that he had already discussed this with Family Liaison and they are aware, he is just waiting to hear back. I clarified 'so do you want to go through the booklet' and he said 'no'."

28. In response to concerns raised by the Trust that they do not have the skills necessary to care for Alta following extubation, the parents have engaged the services of a private nursing agency for the provision of specialist care at the parents' property, Skycare Nursing. Whilst the father asserts in his second statement that the care of Alta will be shared over a 24 hour shift between two experienced, senior live in nurses, the initial letter of 6 September 2021 from that agency confirming arrangements does not appear on its face to evidence a recognition of the complexity of the task that was being asked of it. In particular, no reference is made to the fact that the task is to provide end of life palliative care following the extubation of Alta. A further letter dated 20 September 2021 does acknowledge that the task of caring for Alta at home would be palliative in nature.

29. In response to this proposal, Dr B gave evidence that Alta will need access to robust, high quality nursing care which could be provided in hospital or hospice. Further, Dr B noted that the CVs provided to date by Skycare Nursing indicate one proposed nurse last worked in an ICU sixteen years ago and the other has never worked in an ICU. During his oral evidence he expressed further concerns regarding apparent mistakes in additional CVs provided (for example, claims of nursing roles that do not exist, in the form of a community based PICU nurse, and claims of PICU experience at one of the Trust's hospitals that does not have a PICU). Dr B did however concede that one of the CVs appeared to describe an appropriately qualified PICU nurse, albeit that the appropriate shift timetable would require 5.5 PICU nurses.

30. Within this context, there is no current indication from Skycare Nursing of how it intends to co-operate with the Community Nursing team with respect to Alta's transfer, how it proposes to facilitate its staff spending some time with Alta on PICU prior to any discharge and liaising with the nursing staff so they can get to know Alta and understand her current clinical condition and nursing requirements. In his fifth statement, Dr B states that in an effort to resolve these issues he emailed Skycare Nursing on 13 and 15 September 2021, without response, and telephoned daily on 13, 14 and 15 September 2021 but the telephone was never answered nor multiple voicemail messages responded to.

31. The Trust further contends that the parents have, even after all avenues of appeal were exhausted, refused to engage in discussing the Advanced Care Plan (hereafter "ACP") that will provide the detailed arrangements for the withdrawal of Alta's end of life care. Dr B informed the court that the ACP is a subset of a care plan for Alta with a focus on the problems that might arise during and after extubation. It is a document

that pre-defines the care and the boundaries and gives some common clinical scenarios and how they will be responded to.

32. The Trust further asserts that the parents have, in any event, made clear that they could not agree to the administration of any medication that would suppress Alta's respiratory effort, that they consider that Alta should not be given pain killers unless it is "100% certain" she is in pain and that they do not accept that her condition has, consistent with her terminal prognosis, further deteriorated since May of this year. Finally, and within this context, the Trust asserts that whilst the parents now contend before this court that they will be willing to discuss the ACP, including the specific matters set out above, the Trust has received correspondence from the solicitors for the parents specifically admonishing it for being "gravely disrespectful of their religious beliefs" in seeking to discuss the administration of medication that may suppress respiratory effect. The Trust further relies on what it says is evidence of the parents simply not accepting the reality of Alta's condition. In this context, the nursing notes for 10 September 2021 relate as follows:

> "At 16:10 - seizure presented as hiccups and tongue twitching. When parents were informed they insisted that Alta was perfect, that she was not having a seizures, and they refuse for any treatment to be given until a doctor would come and explain to Dad. I informed him and Mum that we understand they have parental responsibility and we uphold consent and we would not go behind their backs. Dad seemed happy with this response."

And

> "Explained to mum that we felt that Alta was having a seizure and that if it carries on we would need to give Buccal after 30 minutes. Mum started texting and telling me that these hiccups and breathing are normal for Alta and that she is fine and she didn't see a problem. Dad returned to the unit and they were conversing in Yiddish. They were both becoming very agitated and saying that Alta is perfect, she doesn't have seizures and that we are lying and going behind their back. At this point [GA] returned to the bedspace and I informed her about the seizure activity. I went to get some buccal midazolam from the cupboard and informed co-ordinator [ES] and deputy nurse in charge [FB] of what I had overheard and of parents attitude towards the nursing staff. Dad stated that we can not give Alta any medication without their permission and that he wanted the medic to come and speak to him before we do anything".

33. Entirely understandably, and again as is their right, in seeking to preserve the life of their daughter, the parents have sought the intercession of politicians, religious leaders and Heads of State. By way of example, the court is aware that on 21 June 2021, and in the context of the father being a US Citizen, representations were made seeking the intervention of the President of the United States by Republican members of the US Congress. The court is further aware that representations have also been made to the Prime Minister of the United Kingdom by a Democratic member of the United States Congress. Within this context, it is important to make clear that this court could not have received, and has not received, any representations from Parliament or the Executive, or from any other public institution in this or any other jurisdiction, with respect to the outcome of this matter.

34. Within the context of these wholly understandable efforts on the part of the parents however, this matter has attracted a significant amount of coverage and comment in the press and on social media, both domestically and in other jurisdictions. In particular, the court's attention has been drawn to an interview with the parents in the Manchester Evening News in which pictures of the rented property where the parents contend Alta's extubation should take place were published. That publication was syndicated to other outlets, and the information it contains remains available online notwithstanding that the Manchester Evening News has now removed the piece.

35. In these circumstances, in his fifth statement Dr B raises concerns regarding Alta's security should life sustaining treatment be withdrawn at the property rented by the parents. In particular, Dr B states as follows:

> "[41] The Trust has specific concerns for Alta's security and safety if withdrawal of mechanical ventilation were to take place at the family home. An anonymous threat to abduct Alta was telephoned to PICU on 24 August 2021, and on 11 September 2021 a visitor to the hospital left a package of presents for Alta, claiming to be one of their neighbours, but whose name and description was not recognised by the family. Given the family's extensive exposure in the media, including potentially identifiable photographs of their home, I have serious concerns that there may be attempts to provide inappropriate medical interventions in the community following any withdrawal of mechanical ventilation at the family home."

36. In the supplementary bundle of documents provided for the court by the parents for this hearing, the following description is given in the nursing records of the call to the PICU made on 24 August 2021:

> "I answered the call which had been connected via switchboard. I was asked on answering the call to confirm my name. I asked who was calling and they stated they would not tell me until I confirmed my name. I stated I was the nurse in charge on PICU, and I am not prepared to give any further information until I know who I am speaking with. The person stated they have a legal right to know who they are speaking to - to which I reminded them it was them who had called me, and I would not continue this conversation without his details. He started he was called Abraham and he was calling from Israel and he wanted me to know that they were on their way to collect Alta, they had been in contact with dad Abraham and mum Chaya and had been given permission to come and collect Alta and stop the decisions which have been made. He stated this is an international scandal which we should be ashamed of. He stated I should not be obstructive and I should let them take her. I stated this is not something I could facilitate and I would pass him on to the ward manager to continue his discussion. I then put him on hold and made an urgent call to [GC], who contacted Dr B for advice. [GC] took over the call and will complete her own entry to document her conversation."

[GC]'s recording of the call is as follows:

> "PCC Consultant Called at 01:57 - I sought advice & guidance sought from PCC Consultant B immediately without delay. His advice was to confirm

> that I could not discuss this matter and to end the call (politely). I took the phone from [GA] and introduced myself as the Paediatric Critical Care ward manager on duty. Caller: Confirmed he was called Abraham and "acting on parents wishes to come in peace and collect Alta Fixsler". Myself: I stated that I can only discuss parents wishes with themselves and not himself, thanked him for his call and said goodbye. As I was placing the phone down Alta's parents passed by the nursing station on their way out of PICU. I felt this was not the appropriate point to discuss this matter with themselves and therefore let them leave the department and did not follow behind them to open a conversation."

37. The nursing entries for the further incident that occurred on 11 September 2021 read as follows:

> "14:38 Significant Event: Time of Event: 13:45; Summary of event: Some unknown Woman came to visit Alta with a bag of gift at the entrance of PICU, spoke with [DI], did not allow to enter in and see Alta. Received bag of gist containing a doll, book, watch and Magnet, kept it near Bed, to inform and show parents when they visit her."

And:

> "I introduced myself and explained I had been with Alta the previous night. Refer to significant event (11/09/21). Mum asked who the bag of presents was from, because she explained it could not have been a member from their community, as she stated she did not recognise their name in the book. I explained to Mum that the individual was not let onto the unit. I reassured her we have security outside and we do not let individuals into the unit without a green wrist band. I informed the nurse in charge of Mums concerns. Mum was grateful for the care Alta was receiving. Mum left at 20:10."

38. At the hearing before this court on 9 September 2021, Mr Quintavalle made clear that the parents did not dispute that a call was made to PICU on 24 August 2021 and deprecated such conduct in the strongest possible terms. However, in his final statement the father now appears to doubt the credibility of the hospital's assertions with respect to these concerning incidents, suggesting that the hospital has repeatedly changed its version of events regarding the incidents.

39. The court also has before it details of the religious requirements that mark the passage from life to death in the Jewish faith, together with a helpful statement from Rabbi Goldberg in this regard. In summary, the evidence before the court on this issue is as follows:

    i) When death is imminent a window must be opened and a candle lit, which must remain alight until from the point death is expected to the point the body is taken for the Tahara, the traditional process of preparing the body for the final journey to Heaven. A quorum of ten males should attend and say Vidui, Tehilim and Pesukai Yichud and try to say the Posuk "Shema Yisroel" as death occurs. The family should ask for forgiveness from the dying patient, who should not be left unattended. The specific guidelines and laws as to

where to stand around the bed must be followed. At times (depending on status) the dying person may not be touched. Nothing is permitted to hasten death.

ii) Following death, the windows must remain open, the deceased must not be left alone and the body may not be touched for approximately 20 minutes. The eyes and mouth must be closed, preferably by a relative. The deceased's face must be covered and a candle lit and placed near the head of the deceased. Bloodied sheets, clothing and medical equipment must be saved but any drinking water in the room should be discarded. The deceased must be placed on the floor and Shmirah, the ritual of guarding the body, begins. At least two Shomrim will sit with the body for the entire time between death until burial. Those who do Shmirah are not the primary mourners and may be grandchildren, community volunteers or friends.

iii) With respect to the funeral, arrangements may not be made before the person dies. Burial should take place within 24 hours of the time of death. There should be no delay in obtaining a death certificate and repatriation to Israel.

iv) With respect to food, Orthodox Jews must keep a strictly kosher diet, that is, a diet which complies with the Jewish dietary laws and which is rigorously observed in considerable detail.

v) Within the foregoing context, the requirements of Shabbos, the Sabbath day, continue to apply from Friday evening at sundown to Saturday night after nightfall. During that time Orthodox Jews are prohibited from doing a melocha (creative 'work' as defined by Jewish law) nor may they engage in everyday activities including writing, using the telephone, travelling by car or other means of transport, switching lights on or off, or using any electrical equipment, including activating automatic doors or lights. Cooking is also forbidden and all food served on Shabbos must be prepared beforehand. The prohibitions also prohibit asking a non-Jew to perform any prohibited tasks.

40. Having regard to the religious duties and obligations that I have outlined above, the identified children's hospice has indicated, following a meeting with the parents and Rabbi Goldberg, that it can accommodate the following religious requirements were Alta to be extubated at the hospice:

i) The hospice can accommodate a quorum of ten adults in Alta's room from the time she arrives to the time she dies in order to complete the prayers and rituals for the dying.

ii) The hospice is able to accommodate a candle being lit and placed by Alta's bed from the moment of extubation until her body is moved after death.

iii) The hospice is able to accommodate adults as Shomrim to sit with Alta's body for the entire time between death until burial.

iv) The hospice is able to confirm that the family can be given sole use of a designated area to seek to ensure that if Alta needs to be moved no music,

singing, smoking, eating or idle talk will occur whilst Alta's remains are present.

v) The hospice has experience in, and is able to confirm that the parents will be able to obtain a death certificate and the necessary paperwork for the release of the body so that it can be repatriated to Israel without any delay regardless of the time of day or the day of week Alta's death may occur.

vi) With respect to diet, the hospice has confirmed that the family will be able to have sole use of a kitchen, lounge and dining room as well as bedrooms and that it will purchase new utensils and cookware for the family's use, albeit that kitchen appliances will have been used previously and cannot be changed. The hospice is willing to adhere to any specific cleaning requirements that are needed for the family.

vii) The hospice has confirmed it has hotplates to keep food warm on the Jewish Sabbath and that it will purchase a larger hotplate if required.

viii) The automatic doors at the hospice can be deactivated and family members advised as to alternative facilities that will avoid triggering automatic lighting.

41. Within the context of the accommodations that the children's hospice is prepared to make with respect to the parents' religious obligations, the father and Rabbi Goldberg contend that the following problematic issues with religious observance remain in the context of the extremely strict nature of the religious obligations placed upon Orthodox Jews, which problems the parents contend render the option of the hospice unsuitable:

i) If Alta were to survive for a period after extubation then, given the distance between the community and the hospice, it will be hard to ensure a quorum of ten males can attend from the time death is expected and to try to say the Posuk "Shema Yisroel" as death occurs.

ii) The father would be denied the ability to pray in a synagogue three times per day as he is required to do and would be denied the opportunity to practice his religious faith on a Saturday as he would be strictly forbidden from travelling from the hospice in a car.

iii) If Alta were to die on a Saturday, it would not be possible for a quorum of ten adult males to be assembled, again because they would not be permitted to travel by car. The parents would be isolated from their community.

iv) There is a lack of Kosher food shops and restaurants in proximity to the hospice, which prevent the parents observing a Kosher diet.

42. Finally by way of evidence, the court has the benefit of a report from the Children's Guardian prepared on 27 September 2021. The parents have refused to meet with the Children's Guardian prior to this hearing. In the circumstances, the Children's Guardian was denied the opportunity to discuss with the parents their preferred option of Alta being moved to the property rented by the parents for the withdrawal of

treatment. The parents also withheld their consent to the Children's Guardian visiting Alta for the purposes of preparing the final report directed by this court.

43. In his statement, the father alleges that the parents have chosen this course because the Children's Guardian has displayed insufficient compassion and sensitivity towards them and has wrongly suggested that they have neglected Alta in hospital (although the correspondence contained in the court bundle suggests a different reason for the parents being unwilling to meet with the Guardian, namely that the Guardian asked questions of the mother at their first meeting that were inappropriate for an Orthodox Jewish woman). The assertion by the parents that the Children's Guardian has been insufficiently compassionate, and has wrongly accused them of neglect, appears to stem from the following paragraphs of the report of the Children's Guardian:

> "[12] I have previously commented that for over a year of Alta's life (March 2020 and June 2021) she was devoid of expressions love and attention from her kin. This concerns me greatly, when thinking about what children need in terms of emotional warmth, stimulation, and consistency from their parents. Whilst her parents have started visiting more frequently since these proceedings were issued in December 2020, these visits are sporadic, often at unusual times and last for only a couple of hours on each occasion. As such I continue to be concerned that the parents do not have a full understanding of Alta's daily life experiences and what it might be like to be her."

And:

> "[17] Currently it continues to be the case that Alta's needs continue to be met almost exclusively by professionals. I understand that the parents say that they have more recently sought to be trained in tracheostomy care but the reality is that they have not met any of her care needs since she was a very young baby in PICU and their lack of commitment to visiting Alta even now precludes any real possibility that they would become proficient in doing so in timescales that are compatible with Alta's welfare. The parents would have needed to demonstrate a committed visiting pattern for training re tracheostomy care to begin and to visit Alta every day for at least two weeks. For Alta the time for her needs to be met by her parents has run out."

And:

> "In my professional opinion I do not believe that either parent is able to keep Alta either physically, emotionally, or psychologically safe. I have been gravely concerned that their actions have demonstrated a lack of regard for the extent of Alta's suffering which they continue to dispute and she continues to lie in a children's hospital without her family consistently present as she has done for most of her life."

44. The parents contend that these passages fail entirely to take account of the fact that the parents were shielding due to COVID-19 for a significant period during the pandemic and that, in fact, since that time they have been visiting regularly and engaging in Alta's care as demonstrated in nursing records relied on by the parents at this hearing and which the parents have placed before the court. It is not necessary

for the court to determine this ongoing dispute for the purposes of determining the issue before it.

45. Within her report, the Children's Guardian contends that it is in Alta's best interests for treatment to be withdrawn at a hospice. In summary, the reasons underpinning this conclusion are as follows:

i) The plans for the withdrawal of treatment from Alta at home are poorly defined and uncertain. Skycare Nursing have not proposed a package of care and will not do so unless moving Alta home is confirmed.

ii) It is not in Alta's best interests to have treatment withdrawn in the context of a poorly articulated care plan that has not been the subject of appropriate discussion between professionals, is untested and is designed to serve the parents' needs rather than Alta's. Alta's vulnerability is significant. Her clinical care, withdrawal from ventilation and palliative care needs to be managed by people who can keep her safe.

iii) There is an insufficient level of co-operation between the parents and professionals to ensure the efficacy of the plan the parents put forward. The mother and the father are refusing to speak to professionals, they will not work with them and they do not accept what they say. The parents have not engaged with the Advanced Care Plan and object to the use of benzodiazepines and opiates in managing her pain as she passes away "unless it is 100% certain she is suffering". The high level of commitment that would be required from the parents if Alta were in a non-medical environment is not one which has been evidenced by them to date.

iv) The implementation of a package of care at the rented property to support the withdrawal of treatment from Alta in that environment, and the need for the Trust to ensure that the level of care on offer was sufficient, would take six weeks, resulting in a further period during which Alta would be enduring pain and suffering on top of the period since the decision of the court in May this year.

v) Within the context of the publicity that this case has generated and the strong feelings that it has aroused, the rented property risks becoming a focus for those who do not have Alta's welfare interests at heart. This may make it an unpleasant and undignified environment for her end of life care, as well as potentially making the provision of that care difficult. Within this context, in her final report the Children's Guardian observes as follows:

> "[15] There has been an extensive and local, national, and international media campaign. I have found it very difficult, on her behalf, to see her medical information, personal circumstances, and distressing pictures of her at her most vulnerable all in the press. It is my view on behalf of Alta that she should have been afforded more privacy and whilst I understand that it was the parents desire to highlight what they regarded as an injustice via a media campaign, I do not believe Alta should have had her privacy invaded in such a

> way. I hope that her death will not be attended by a similar level of public and media scrutiny."

vi) A children's hospice would offer a peaceful and protected environment for Alta and her parents to spend the last moments of her life together, particularly in circumstances where the parents have visited the hospice and felt reassured by what was able to be offered, even if it was not their preferred option.

46. Within the foregoing context, the Children's Guardian concludes her welfare analysis as follows:

> "[60] In my professional opinion Alta's dignity continues to be compromised some four months after the Court made the decision that life-sustaining treatment should be withdrawn. She has been the subject of an extensive media campaign and her privacy has been invaded. I wrote this in my first analysis and still believe the same, 'I do not believe that she has any quality or dignity of life despite the best efforts of the professionals caring for her and her daily lived experiences are painful, isolated, and devoid of love. She cannot interact with her environment in any way and is trapped in her world.'
>
> [61] I wish to end my report with a focus on Alta. She is in pain and spends a lot of time alone save for the professionals who care for her. I sincerely hope that the parents are able to put aside their difficulties with professionals and make a plan with Alta's medical team to give her a peaceful passing. I do not underestimate that to lose a child is the worst pain anyone can ever experience. In recognising Alta's needs as the primary focus I am asking them for the greatest act of love. In any criticism they believe I have made of them I do not ever believe that they do not love her; that knowledge of their love has been a buffer in the sadness all professionals feel for this little girl."

MEDICAL EVIDENCE

47. The medical evidence with respect to Alta's current condition and the location in which life sustaining treatment will be withdrawn from Alta is contained in the statements of Dr B, consultant paediatric intensivist, dated 23 August 2021 and 16 September 2021.

48. With respect to Alta's current condition, Dr B makes clear in his fifth statement that Alta has recently suffered further physiological deterioration, characterised by more frequent and more profound episodes of oxygen desaturation, leading Dr B to consider that it is unlikely that Alta will survive for a prolonged period following withdrawal of mechanical ventilation, albeit it remains possible that Alta may survive for several weeks, or even longer. Within this context, Dr B asserts that it is vital that a safe and sustainable system of care is in place to support Alta, given this possibility.

49. With respect to the question of the location at which extubation of Alta should take place, Dr B further asserts that retaining Alta at the hospital for the withdrawal of treatment carries with it the least risk, as this would involve moving Alta only to a suite at the end of the ward on which she is currently being treated. With respect to

moving Alta outside the hospital environment, either to a hospice or to the property proposed by the parents, Dr B identifies two specific risks.

50. First, it will not be possible to transport Alta by ambulance without causing her pain and distress in circumstances where, as this court has found, physical intervention and movement cause Alta to suffer muscle spasms which cause pain and discomfort. Whilst this can be mitigated by the use of pain relieving and sedative medications, it cannot be eliminated. Second, in the context Alta's clinical condition having become less stable, episodes of physiological instability may be triggered by movement and repositioning, making it likely that Alta will suffer from periods of physiological deterioration during transfer. Within this context, Dr B considers it to be possible, although unlikely, that Alta could suffer a cardiac arrest during transfer.

51. Within this context, and from a medical perspective, Dr B opines that a move to a hospice for Alta would be more manageable than a move home in circumstances where the former represents a move from one specialist clinical environment to another. In his fifth statement, Dr B notes in particular that hospice nursing staff are experts at providing palliative care and have specific expertise in assessing terminally ill patients and managing their symptoms with appropriate interventions and medications.

52. Against this, Dr B considers that there would be a high level of risk in managing Alta's medical care and pain at the parents' property. Further, he contends that it is, in fact, impossible to facilitate this at home rather than in a clinical environment without a strong, open and co-operative relationship with the parents, which Dr B contends does not exist in this case. As I have noted, the parents contend that they will co-operate fully following the decision of this court regarding the location at which extubation will take place.

53. With respect to the mechanism of the withdrawal of life sustaining treatment by way of extubation, Dr B states as follows in his second statement:

> "[22] Alta will be ventilated during any transfer using a specialist portable critical care ventilator. These complex devices are not used in community settings and no community staff will have the training to use them. Whilst there is some flexibility, withdrawal of mechanical ventilation, as set out above, would need to take place within around one hour of arrival of the transfer team at their destination, to allow the transport team members to return to their usual duties, and care for other critically ill children."

54. Within this context, in his first statement, Dr B concludes as follows with respect to the proper clinical course regarding Alta's extubation:

> "[22] It is the agreed clinical view of the clinical team that withdrawal of mechanical ventilation should take place either in the PICU or at [the hospice]. My 'preferred option' would be for this to happen at [the hospice]. I believe this would be in everyone's best interests. Firstly, for Alta, she will experience the benefits of the hospice environment in that they are obviously the experts in delivering palliative care. For the family, [the hospice] can meet all of the family's very specific requirements, such as the request to accommodate an unusually large number of visitors,

> which, although it could be agreed by the Trust given the exceptional circumstances, would be a breach of the Trust's COVID policy and may impact upon other patients and their families, and the functional capacity of the unit. The parents have also made positive comments about [the hospice]. Thirdly, for other patients in the region, withdrawal at [the hospice] represents a more appropriate use of healthcare resources overall and would allow us to admit another critically ill child to PICU at a time of considerable national pressure on PCC beds."

THE LAW

55. The legal principles the court is required to apply in determining the dispute as to the location at which life sustaining treatment should be withdrawn from Alta are as follows:

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 the step proposed 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.

iv) 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.

v) 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.

vi) The court must consider the nature of the medical treatment or step in question, what it involves and, where appropriate, its prospects of success, including the likely outcome for the patient of that treatment.

vii) Each case is fact specific and will turn entirely on the facts of the particular case.

viii) 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."

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

56. Within the foregoing context, and as acknowledged by the solicitors for the parents in their letter to the hospice dated 13 September 2021, the issue now before the court falls to be decided placing Alta's welfare as the court's paramount consideration.

57. The parents rely on Art 9 of the ECHR in support of the proposition that the ability of the parents to provide fully and properly, on behalf of Alta and for themselves, the necessary religious prayers and rituals at the time of death is protected by that provision of the ECHR. On behalf of the parents, Mr Quintavalle further relies on the case of *Pretty v United Kingdom* (Application No. 2346/02) at [64] in support of the submission that the right to determine the manner of passing in the last days of one's life is protected by Art 8 of the ECHR. Within this context, I note the following passages of the judgment of the Court of Appeal in this matter:

> "[81] The family's religion and culture are fundamental aspects of this child's background. The fact that she has been born into a devout religious family in which children are brought up to follow the tenets of their faith is plainly a highly relevant characteristic of hers. Under s.1(3)(d), the court is required to have regard to the fact that Alta is from a devout Hasidic family which has very clear beliefs and practices by which they lead their lives and that, if she had sufficient understanding, she too would very probably choose to follow the tenets of the family religion. I agree with Mr Simblet that this is a central part of her identity – of "who she is". It is unquestionably an important factor to be taken into consideration. But it does not carry pre-eminent weight. It must be balanced against all the other relevant factors.
>
> [82] None of the factors in the checklist has any presumption of precedence. The weight to be attached to each factor depends on the circumstances of the case and the final decision is that of the court. Whilst in an individual case the child's wishes and feelings, and her background and characteristics, including the religious and cultural values of the family of

> which she is a member, may attract particular weight, in all cases they start with an equal value to that of all the other relevant factors."

58. Within this context, it is well established that insofar as there is a conflict between the family's rights under Art 8 and Art 9 and Alta's best interests, it is Alta's best interests which must prevail.

DISCUSSION

59. Based on the evidence before the court, and applying the legal principles that comprise the law in this jurisdiction, I am satisfied that it is in Alta's best interests for treatment to be withdrawn at the children's hospice identified in this case. My reasons for so deciding are as follows.

60. I am not able to accept the submission made on behalf of the parents that the court has already ruled that it is in Alta's best interests for mechanical ventilation to be withdrawn at home where that is the preference of her parents and that, accordingly, the Trust is prohibited from re-opening that issue. As I have described above, following the decision of the court, the parties negotiated the precise terms of the consequent order, which the court approved. That order, and the appendix referred to in it, makes clear that the implementation of a parental preference is subject to it being capable of being arranged. Within this context, Mr Coppel and Mr Quintavalle sensibly concede in their Position Statement that whether withdrawal at a particular location can be arranged encompasses consideration of the suitability of the premises and nursing and security arrangements. Having regard to the paramount nature of Alta's best interests that must be the correct position. Within that context, the question for the court comes down to which of the competing proposals advanced by the Trust and the parents before the court can be said to be in Alta's best interests applying the legal principles I have set out above. Within this context, the court must assess the advantages and disadvantages to *Alta* of the competing proposals.

61. Within this context, with respect to Alta's assumed point of view, and as the Court of Appeal made clear in this case with respect to a very young child in Alta's condition the element of substituted judgment in the best interests decision is very limited. Only broad general conclusions can be drawn. In this context, I am satisfied that at the point at which treatment is withdrawn, Alta would wish to be in a position whereby she has access to the maximum level of specialist care available to ensure that pain and discomfort is mitigated, has the company of her family close to her and, in so far as their performance is consistent with her medical care and overall welfare, has performed for her the religious obligations that her parents consider sacrosanct.

62. Within the latter context, whilst I am satisfied that Art 8 and Art 9 of the ECHR are engaged and the court must have particular regard to Alta and her parents' right to, and respect for, private and family life under Art 8 and right to freedom of thought, conscience and religion under Article 9, the clear legal position is that where there is a conflict between a Convention right or rights and Alta's best interests, it is her best interests that are determinative. Whilst religious obligations of the parents and wider Orthodox Jewish community are very important, they remain subordinate to Alta's clinical and welfare needs prior to, during and following extubation.

63. Likewise, whilst the views of the parents regarding the issue in dispute before the court are very important and I have paid very careful regard to them, those parental views are again subordinate to Alta's best interests. Within this context, as the Court of Appeal noted in this case:

> "[87] The views of parents about their child's welfare are plainly of great importance but, as repeatedly stressed in earlier cases (for example, this Court in *Wyatt v Portsmouth Hospital NHS Trust*), where there is a dispute between parents and clinicians about the serious medical treatment to be given to a child, it is the judge who must decide what is in her best interests."

64. With respect to Alta's medical needs, I am satisfied that the withdrawal of life-sustaining care by way of extubation leading to the cessation of mechanical ventilation is a delicate and specialist procedure, as is the ministration of palliative care following that step being taken. This task is made more challenging by the continuing deterioration in Alta's condition that I am satisfied on the evidence before the court has taken place since May 2021. Most importantly, given the court's findings regarding the level of pain being experienced by Alta, it is *vital* that the care given to Alta prior to, during and following extubation is of a high and expert calibre to ensure that she suffers the minimum pain and discomfort possible following the removal of mechanical ventilation. Within this context, and given the inherent uncertainty in Alta's life expectancy following the removal of ventilation, I agree with the evidence of Dr B that it is vital that a reliable, safe and sustainable system of care protected from disruption is in place to support Alta. In determining which of the competing options before the court is to be preferred, I have given significant weight to the factors set out above.

65. Within the foregoing context, I turn to the competing options advanced before the court by the parents and the Trust. With respect to the parents' proposal, I accept that there are some significant advantages to the withdrawal of treatment taking place at the property rented by the parents. It is correct that this the option of palliative care at home has been discussed with the parents a number of times over the course of Alta's illness, as identified in the father's statement and the Position Statement of the parents. The location of the rented property would have advantages for the parents in terms of the obligation to continue their religious observance at the synagogue and would not involve the potential interruptions to those obligations, and the obligations that will attend the death of Alta, that may arise from the use of the children's hospice. It would also allow the parents ready access to their community at a very difficult time. There would be less disruption for Alta's sibling.

66. Against these matters however, a number of powerful counterpoints arise in respect of the parents' proposal. Whilst the parents advance their argument on the basis that the withdrawal of treatment should take place "at home", as I have noted this is not what would occur. Were the court to prefer the position of the parents, extubation would take place at a property rented by the parents for that purpose in order to meet concerns regarding the suitability of the family home. Within this context, it is relevant in my judgment that Alta has never been to the family home, having spent her entirely life either in the NICU or PICU, or to the property now rented by the family. Further, and in accordance with the findings made in my first judgment in this matter, Alta has no conscious awareness and, accordingly, would not be aware of

or understand that she had been taken "home" for the purposes of withdrawing life sustaining treatment.

67. Further, I am satisfied that the parents' proposal is antithetic to the effective implementation of a reliable, safe and sustainable system of high calibre care protected from disruption is in place to support Alta that I have found is vital to ensure her welfare.

68. The parents accept that, as matters stand, they are not equipped to meet Alta's clinical needs. Whilst the parents place this deficiency at the feet of the Trust in alleging the Trust has failed to respond to increasingly urgent requests for training, I am doubtful that that is an entirely accurate picture having regard to the entry in the nursing records indicating the father declining a teaching opportunity at around the time the parents' solicitors were writing to the Trust. However, given the foregoing concession regarding their current abilities it is not necessary for me to make findings in that regard. Alta is in pain and it is plainly not in her best interests for further delay whilst the parents undertake the training required. Within this context, the parents advance as the solution the employment of private agency nursing staff to care for Alta.

69. Mr Coppel and Mr Quintavalle submit that where the standard of care required to supplement the community nursing team and the GP is that of a properly trained parent, the agency nurses put forward by Skycare Nursing are plainly sufficient to allow withdrawal of life sustaining treatment to take place at the property rented by the parents. Whilst I accept the logic of that submission, serious difficulties remain. There has to date been very little communication from the nursing agency with the Trust. Dr B's evidence, that his emails of 13 and 15 September 2021 to Skycare Nursing were not responded to and his telephone calls of 13, 14 and 15 September 2021 were not answered nor multiple voicemail messages responded to, was not challenged in cross-examination. Within this context, there has been little or no liaison between the agency nurses and the treating clinicians regarding Alta's needs, no visit to the hospital to facilitate exchange of information or to get to know Alta. As such, there has been no appropriate and necessary exchange of information between professionals who will be involved in ensuring Alta's welfare during difficult and highly sensitive medical procedures. Within this context, I accept the evidence of Dr B that whilst a very loose proposal has been made for the deployment of private agency nursing staff, there can be no confidence that it is capable of forming part of the reliable, safe and sustainable system of high calibre care protected from disruption that I have found is vital to ensure Alta's welfare.

70. Further, I am satisfied that these considerable difficulties in the context of the parents' proposal are exacerbated by what all parties accept is a breakdown in the relationship between the parents and the Trust. It is plain from the statements of the father that there has been a complete breakdown of trust between the parties. Within this context, I accept as almost self-evident the evidence of Dr B that for an extubation at home to be successful there needs to be a close and co-operative working relationship between the parents and the treating clinicians, including direct communication between the doctors responsible for the management of that difficult and sensitive step and the family, halted in this case at the request of the parents. The idea that, in what could be come a fast-evolving medical situation, Alta's welfare could be protected in the context of communications that have to be routed via lawyers is self-

evidently specious. Whilst the parents state through Mr Coppel that, once the court has made a decision, they would meet with doctors, in my judgement the approach of the parents to date gives the court little confidence that that would, in fact, be the position when the time came for extubation to take place.

71. This conclusion is reinforced by the parents' attitude to the compilation of an ACP. In order to make Alta as comfortable as possible, the palliative care team will administer medication to ease her pain. This is likely to include diamorphine, which will have the secondary effect of suppressing her respiratory effort. The evidence before the court demonstrates that the parents have not engaged with the Advanced Care Plan and object to the use of opiates in managing her pain as she passes away unless it is "100% certain" she is suffering. Further, it is clear from the evidence before the court that that parents, at best, struggle to accept the finding of the court that Alta is in pain and that her condition has deteriorated in the context of her terminal prognosis. All of this is understandable given their strongly held convictions, informed by the strict requirements of their faith as Chassidic Jews. However, and in that context, I am not able to conclude that the position is likely to change in the manner posited by Mr Coppel such that a sufficiently co-operative working relationship will develop to permit the safe withdrawal of life sustaining care at the rented property.

72. In particular, and in the foregoing context, I was struck by the assertion made through Mr Coppel at this hearing that, were the court to accede to the option of Alta's life support being withdrawn at home, the parents would accept as part of the ACP the use of medication that reduced Alta's respiratory effort. That statement stands in *absolute* contradiction to the unassailable religious principles prayed in aid by the parents throughout these proceedings, including at this hearing. Indeed, it will be recalled that the Trust was accused through the parents' solicitors of acting in a manner that was gravely disrespectful of their religious beliefs in seeking even to raise certain of these issues with them. Within this context, I regret that I have no confidence that the parents would participate willingly in a meeting with the Trust to settle the ACP even were the court to accede to their proposal that life-sustaining treatment be withdrawn at the property they have rented. Once again, this militates heavily against the successful implementation of a reliable, safe and sustainable system of high calibre care protected from disruption that I have found is vital to ensure Alta's welfare.

73. Finally with respect to the parents' proposal, I am satisfied on the evidence before the court that there is an appreciable risk to Alta's security were treatment to be withdrawn at the property rented by the parents. It is accepted that pictures of the property rented by the parents have appeared in the Press and online. An article in the Manchester Evening News which included photographs of the parents (contrary to the reporting restriction in force at the time) and showed the interior and exterior of the rented property. Whilst it is no longer available on the MEN website, there were several articles, including those published by the Daily Express and Daily Mirror, which carry the same photographs and the same level of detail, which information remains freely available on the Internet. The approximate location of the house was also described in an article for Sky News as recently as 20 September 2021. Further, it is plain that this case has, in the manner I have outlined earlier in this judgment, provoked understandably strong public sentiments and an ongoing campaign to reverse the decision of this court. Within that context, I accept the evidence before

the court that the Trust received a verbal threat to abduct Alta from the hospital on 24 August 2021 and the attendance of an unidentified adult at the ward on 11 September 2021.

74. In the foregoing circumstances, I am satisfied on the evidence before the court that there is an appreciable risk that Alta's security could be threatened were the withdrawal of treatment to take place at the property rented by the parents. The risk of a breach in security is heightened given the very sensitive, solemn task ascribed to treating nurses and doctors with respect to Alta. Once again, the existence of such an appreciable risk is entirely antithetic to the successful implementation of a reliable, safe and sustainable system of high calibre care protected from disruption that I have found is vital to ensure Alta's welfare. The environment in which Alta passes must be conducive to a peaceful and dignified death absent the threat of disruption and conflict. I am not satisfied that the employment of a private security firm by the parents will meet these risks in the circumstances of the case.

75. Turning to the option of the PICU, there are clearly manifest advantages to this being the location at which Alta is extubated and I accept the evidence of Dr B that this location carries the lowest risk of adverse impact on Alta. Withdrawal of life-sustaining treatment at the PICU would allow Alta to be cared for by nurses and doctors who are already expert in providing her with high quality care, who have cared for her since birth and who are highly experienced in the withdrawal of ventilation given that the vast majority of planned withdrawals take place in PICU. They also would have immediate access to the full resources of the PICU in order to manage Alta's passing. Alta would not need to be transferred out of the hospital. There are however, also some disadvantages to this option for the family in that it will be harder (and certainly harder than at the children's hospice) for the parents to fulfil the detailed religious obligations that will attend the death of Alta, as well as the parents' daily religious obligations generally. The breakdown in the relationship between the parents and the Trust may also bear on the extent to which the PICU is an environment conducive to the family's needs at the time of Alta's death.

76. Finally with respect to the option of the identified children's hospice, in my judgment this option has considerable advantages over both the option of withdrawal of treatment at the property rented by the parents and withdrawal of treatment at the PICU, particularly when seeking to achieve an outcome in Alta's best interests that is proportionate to the aim it is sought to achieve.

77. As I have already made clear, Alta's best interests are the court's paramount consideration and, within that context, the court is concerned to ensure that, having made the declarations it did in May 2021, there is in a place a reliable, safe and sustainable system of high calibre care protected from disruption to manage the withdrawal of Alta's treatment and ensure her care and comfort prior to death. Within this context, whilst a move from the PICU will mean that the current treating team will be lost to Alta, hospice nursing staff are experts at providing palliative care and have specific expertise in assessing terminally ill patients and managing their symptoms with appropriate interventions and medications. Within this context, Alta will receive care from highly experienced palliative care nurses, who provide end of life care for children with complex needs on a daily basis. That care will be informed by the ACP agreed at the hospital.

78. I also bear in mind of course, that it is also the case that transfer to the hospice will, on the evidence of Dr B, cause Alta a degree of pain and distress in circumstances where, as this court has found, physical intervention and movement cause Alta to suffer muscle spasms which cause pain and discomfort. This however, can be mitigated over the course of the short journey by the use of pain relieving and sedative medications and will be further mitigated by moving from one clinical environment to another clinical environment, albeit it cannot be eliminated. The RMCH and hospice are experienced in transition planning as between those two locations and transfer has been effected between the two clinical sites many times. I also bear in mind that, Alta's clinical condition having become less stable, episodes of physiological instability may be triggered by movement and repositioning, making it likely that Alta will suffer from periods of physiological deterioration during transfer. However, Dr B considers that, whilst possible, it is unlikely that Alta would suffer a cardiac arrest during the short transfer.

79. Whilst subordinate to the paramount consideration of Alta's welfare, I nonetheless consider that an important factor in favour of the hospice is that this option will allow the majority of the religious obligations attendant on Alta's death to be fulfilled by the family. The correspondence before the court shows clearly that the hospice is extremely sensitive to the families cultural and religious needs. Mr Coppel made clear in his submissions that the parents are very happy with the assistance they have had from the hospice and happy with everything done by it thus far.

80. I accept that on the evidence of the father and Rabbi Goldberg some issues regarding the compliance with strict religious obligations for Orthodox Jews would remain were the children's hospice to be the option preferred by the court. In particular, there would potentially be difficulty in ensuring that the religious obligations of a quorum of ten male adults to attend from the time death is imminent, and the father attending the synagogue three times a day to pray, both of which obligations would become impossible if Alta passed away on the Sabbath, given the prohibition on travelling by vehicle. With respect to the Sabbath obligations I acknowledge that, as made clear in the document before the court that details the religious obligations of Orthodox Jews on the Sabbath:

> "The prohibition on performing melocha is extremely strict and is a concept that is very difficult for non-Jews to understand. Orthodox Jews will go to extreme lengths to avoid transgressing the Shabbos laws, which should be respected and not ridiculed, no matter how irrational these laws may seem."

81. However, and as I have stated above, the secular law this court must apply is equally clear that in so far as there is a conflict between the Art 9 rights of the parents and Alta's best interests, it is Alta's best interests which are determinative. Within this context, the remaining difficulties articulated by the father and Rabbi Goldberg with respect to religious observance are not sufficient in my judgement to render the option of the hospice antithetic to *Alta's* best interests. This is particularly so in circumstances where the risk of the applicable religious obligations not being performed can, to some extent, be mitigated by extubation of Alta taking place immediately following the Sabbath, since it is Dr B's evidence that Alta is likely to pass away within a short time of extubation. This would tend to favour extubation taking place on a day that reduces the risk of the parents not being able to ensure that the solemn religious obligations that will attend Alta's death.

CONCLUSION

82. Balancing the matters that I have set out above, and applying the legal principles that I must, I am satisfied that it is in Alta's best interests for the withdrawal of life-sustaining treatment to take place at the children's hospice identified by the parties. I am satisfied that this option best accommodates Alta's welfare need for specialist care at the end of her life under a reliable, safe and sustainable system of high calibre care protected from disruption, whilst allowing, in so far as possible and consistent with Alta's best interests, the family and the community to perform the sacred religious obligations of the Orthodox Jewish faith. In the circumstances, and for the reasons I have set out, I am satisfied that it is appropriate to make the order that is set out in the Schedule attached to this judgment.

83. I recognise that the parents, and others in the wider community, will struggle to understand why the court has determined that it is not in Alta's best interests for life sustaining treatment to be withdrawn at the property secured by the parents, rather than at the children's hospice. With respect to the parents' position, the question may be asked by many 'Well, why not? Surely, to allow Alta to die at home is the compassionate and merciful course to take?'. The issue before the court must however, as I have made clear, be decided by holding *Alta's* welfare as my paramount consideration. Within this context, whilst the law must be tempered by compassion and mercy, that cannot be at the price of prejudicing Alta's welfare.

84. Further, and as I have already noted, I am conscious that during its currency this case has provoked understandably strong views and sentiments and an ongoing campaign to reverse the decision of this court. However, as I noted in *Barts NHS Foundation Trust v Raqeeb* [2020] 3 All ER 663 with respect to the task that the court is required to perform in these most difficult and sensitive cases:

> "[2] I recognise at the outset of this judgment that such cases, touching as they do on the very nature, purpose and value of human life, raise emotive, complex and contentious issues that generate strong feelings on both sides of the litigation and in the wider public and professional sphere. Be that as it may, it is important to state at the beginning that the duty of this court is to decide the applications before it by reference to the law. The court must, and does disregard the urging of media and social-media campaigns, petitions, and pressure groups and the views of informed and uninformed commentators and opinion writers. The court does so not because the views and opinions of those diverse constituencies are in any way unwelcome or invalid, but rather because the decisions of the High Court in these most challenging of cases are determined solely by application of the law, in order to reach a decision on the seminal question of best interests."

85. I repeat this observation in the context of those representations, arguments and opinions that have been proffered in respect of this case by people in many walks of life and in many different jurisdictions, to which I have referred to above. Those representations, arguments and opinions are neither invalid nor unwelcome, but they do not inform the decision of the court.

86. I also remain conscious that decisions of this nature raise questions regarding the location of the boundary between parental responsibility and the authority of the

State. Within this context, and as I noted in my first judgment, the position that pertains in this case under the law of this jurisdiction, and the basis on which this court intervenes notwithstanding the position taken by the parents, is eloquently described by the decision of the US Supreme Court in *Prince v Massachusetts* (1944) 321 US 158:

> "… 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 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 …"

87. Finally, I remain *acutely* conscious of the fact that the original decision of this court is incompatible with the deeply held Judaic religious beliefs of the parents and that, within that context, they will consider that the option preferred by this judgment further obstructs their religious obligations. However, it remains the position that, as would be the case 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, the court has sought in the decision it has made to accommodate the religious beliefs and obligations of the parents insofar as it has been possible to do so within the context of Alta's welfare being the court's paramount consideration.

88. That is my judgment.

SCHEDULE

CASE NO: MA20P02742

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
IN THE MATTER OF ALTA FIXSLER
AND IN THE MATTER OF THE CHILDREN ACT 1989
AND THE MATTER OF THE SENIOR COURTS ACT 1981

BETWEEN:

MANCHESTER UNIVERSITY NHS FOUNDATION TRUST

Applicant

-and-

ALTA FIXSLER
(By her Children's Guardian)

First Respondent

-and-

CHAYA FIXSLER

Second Respondent

-and-

ABRAHAM FIXSLER

Third Respondent

ORDER

BEFORE Mr Justice MacDonald sitting as a Judge of the Family Division of the High Court on 5 October 2021.

UPON hearing from Counsel for the Trust, Counsel for the First Respondent and Leading and Junior Counsel for the Second and Third Respondents.

AND UPON judgment having been handed down on 5 October 2021, following a one day hearing in this matter.

AND UPON the Court having declared on 28 May 2021 that by reason of her age and minority, Alta Fixsler ('the child') lacks competence and capacity to give her consent to medical treatment.

AND UPON the Court having further declared on 28 May 2021 that is not in the child's best interests for life-sustaining treatment, including mechanical ventilation, to be continued and that it is in her best interests and lawful that she should be moved to a palliative care pathway such that:

a. Mechanical ventilation should be withdrawn; and

b. There shall be clearly defined limits on the treatment to be provided to her after ventilation is withdrawn; and

c. The withdrawal of mechanical ventilation shall take place in accordance with the pathway at Appendix 1 to this Order.

AND UPON the Court having ordered on 28 May 2021 that the Applicant and/or the doctors having responsibility for the treatment of the Child shall be at liberty to treat her in accordance with their clinical discretion, including any decision they make as to removal of ventilatory support.

AND UPON the Court having ordered on 28 May 2021 that the Applicant and/or doctors and nurses treating her shall generally provide such treatment and nursing and palliative care as may be appropriate to ensure that she suffers the least pain and distress.

AND UPON the court having determined at this hearing that it is in the child's best interests for the removal of ventilatory support in accordance with the clinical discretion of the doctors authorised by the order of the court dated 28 May 2021 to take place at the [named] Children's Hospice.

IT IS ORDERED THAT:

1. The removal of ventilatory support in accordance with the clinical discretion of the doctors authorised by the order of the court dated 28 May 2021 shall take place at the [named] children's hospice.

2. The date, time and place of withdrawal are contained in a separate, confidential Schedule.

3. The date, time and place of withdrawal shall not be made public.

4. For the avoidance of doubt, in providing such treatment and nursing and palliative care as may be appropriate to ensure that she suffers the least pain and distress as authorised by the order of the court dated 28 May 2021 is lawful, and the doctors and nurses are permitted in accordance with their clinical discretion to administer medication to mitigate pain.

5. Further and for the avoidance of doubt, in providing such treatment and nursing and palliative care as may be appropriate to ensure that she suffers the least pain

and distress as authorised by the order of the court dated 28 May 2021 is lawful and the doctors and nurses are permitted in accordance with their clinical discretion to administer medication that may have the secondary effect of reducing the child's respiratory effort.

6. If any further issue arises in respect of withdrawal of life-sustaining treatment, including ventilatory support, the parties shall have permission to apply to Court for further directions. Any such application should be heard before Mr Justice MacDonald.

7. There is no order as to costs.

SCHEDULE

[Redacted]