



Neutral Citation Number: [2022] EWHC 2229 (Fam)

Case No: FD22P00400

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 24/08/2022

Before:

THE HONOURABLE MR JUSTICE HAYDEN

Between:

**Birmingham Women’s and Children’s NHS Foundation
Trust**

Applicant

- and -

- (1) J**
- (2) M**
- (3) F**

Respondents

Miss Nageena Khalique QC (instructed by Weightmans LLP) for the Applicant
Ms Victoria Butler-Cole QC (instructed by Cafcass Legal) for the First Respondent
Mr Ian Brownhill (instructed by Irwin Mitchell LLP) for the Second and Third Respondent

Hearing dates: 16th and 22nd August

Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....
THE HONOURABLE MR JUSTICE HAYDEN

The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the children and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

MR JUSTICE HAYDEN:

1. This is an application made by the Birmingham Women’s and Children’s NHS Foundation Trust, pursuant to the inherent jurisdiction of the High Court, to grant declaratory relief. The declaration is sought in respect of a 6-year-old girl (J) who is suffering from a very rare terminal neuro-degenerative genetic condition, known as NRROS-gene deletion (negative regulator of reactive oxygen species). The NRROS-gene encodes proteins which are essential for brain development and function. The abnormality of that gene causes neurodegeneration, including febrile seizures, infantile spasms and focal and myoclonic seizures. The Trust seeks a declaration that it is in J’s best interests for her not to be given mechanical or invasive ventilatory support and for what are referred to as, “*ceilings of treatment*” to be put in place. J is represented by her Guardian, who supports the Trust’s application. J’s parents strenuously resist it. Though this hearing has taken place in open court, the family has been vigilant to protect J’s privacy. Her name and anything that might identify her has been protected by order of the Court and continues to be.
2. It is necessary to set out the medical background which, it should be noted, is extensively agreed between the parties. It is also important to emphasise that whilst the parents disagree with the Trust’s application, they do so, in my judgement, primarily on religious and cultural grounds. They do not question the commitment, professionalism, and sincerity of all the medical professionals involved. On the contrary, they have an obvious respect and gratitude to them for all they have done for their daughter. That respect is entirely reciprocated. All who have encountered this family have admired their care, compassion, and generosity of spirit. Their courage and resilience have inspired all who have been involved in their lives, in whose number I include myself.

Medical history

3. J was born, at term, after an uneventful pregnancy in Lebanon by emergency section due to breech presentation and foetal distress. Her birth weight was 3.2 kgs. She was born in good condition and required no resuscitation. She suffered from gastro-oesophageal reflux and had an infection at around six months of age for which she received antibiotics for a week. Her early development was normal; she had some delay with her speech but started walking from around the age of one year.
4. J has a younger brother, M, who is 5 years old and in robust health. J was presented to the Worcester Royal Hospital, in December 2017, having suffered a prolonged, generalised tonic seizure with eye rolling. Following this first seizure, J started to demonstrate regression of her motor and cognitive skills and, sadly, went on to suffer a second seizure after an interval of approximately a month. She was started on sodium valproate in January 2018, which was, at least initially, effective in controlling her seizures. However, due to escalation of seizures, levetiracetam and nitrazepam were prescribed during May and June 2018. A CT brain scan demonstrated; *‘multiple areas of calcification predominantly in the sub-cortical and peri-ventricular distribution except for tiny calcification in the lentiform nucleus, no lesions within the thalami. There is ventriculomegaly with dilatation of lateral and third ventricles’*.

5. J was referred to a specialist Paediatric Neurologist in July 2018 and was described as demonstrating “*poor tone, microcephaly, loss of speech and limited eye contact*”. She required nasogastric tube feeding. Dr S Philip, Consultant Paediatric Neurologist, observed:

“She is microcephalic, head circumference is 44.1cm, she has general hypotonia both axially and peripherally. She has good muscle power in her hands and feet. She has no eye contact. She is not able to recognise things, she is not able to communicate. There are no neurocutaneous stigmata except a small café-au-lait spot on her back. There are no significant dysmorphic features”

6. J was investigated at Birmingham Children’s Hospital (BCH); an MRI brain scan demonstrated abnormal areas of calcification within the brain. Her electroencephalogram (EEG) was “*very abnormal*”. Steroids were added to J’s anticonvulsant regime; these initially had a beneficial impact, but this proved to be transient. Different combinations of anticonvulsant medications were tried, including a ketogenic diet. It proved difficult to eliminate her seizures, although they were described as not particularly burdensome in terms of their frequency and duration at this point. In March 2019, J was admitted to Worcester Royal Hospital with fever, vomiting, and a chest infection due to Influenza A. Her seizures became more prolonged and difficult to control. She developed respiratory failure and required intubation and mechanical ventilation. J was transferred, once again, to BCH Paediatric Intensive Care Unit (PICU). J remained in PICU for one month and spent the next 4 months in hospital.
7. An electroencephalogram (EEG), performed on 29 April 2019, is recorded, in the hospital notes as revealing the following:

“sub continuous epileptiform abnormalities bilaterally with right hemisphere prevalence. Rhythmic activity is of reduced amplitude. Multiple brief tonic spasm like events were seen in prolonged cluster associated with bilateral R>L paroxysmal EEG discharge. As the patient drifts off to what behaviourally appears to be sleep (no obvious physiological sleep transient seen) the abnormalities become continuous. In summary there has been a dramatic deterioration of the EEG with frequent brief seizures, non-convulsive status epilepticus in sleep and abnormal rhythms suggesting a diffuse cortical dysfunction.”

I should record that during this admission it was identified that J was suffering from bilateral vocal cord palsy and a tracheostomy was performed on 19 July 2019.

8. Following this, J was reasonably well until September 2020 when she required a further two-week admission in PICU due to a chest infection. J was discharged on home oxygen. There was a further short PICU admission in December 2020 and a longer PICU admission from January to March 2021, when she tested positive for COVID-19 and subsequently respiratory syncytial virus (RSV).

9. An EEG performed in January 2021 demonstrated a background of encephalopathy with several subclinical seizures.
10. It is convenient to record J's hospital admissions in 2021 as they chart her increasing dependency on hospital support:

“17 January - 23 March; BCH (17 Jan - 17 March in PICU)

7 May - 11 May; BCH (transferred to Stoke due to lack of PICU

capacity)

11 May - 17 May; Stoke

31 May - 25 June; BCH (31 May - 25 June in PICU)

3 July - 14 July; BCH (4-14 July in PICU)

26 July - 27 July; BCH (transferred to Stoke due to lack of PICU

capacity)

27 July - 5 August; (Stoke)

5 August - 18 August; BCH (5-18 August in PICU)

22 August - 23 August; BCH (transferred to Leicester due to lack of

PICU capacity)

23 August - late August; (Leicester)

4 September; A&E BCH

6 September - 25 September; BCH (6 -20 September in PICU)

14 October - 27 October; BCH (16-27 October in PICU)

25 November - BCH PICU”

It is important to identify that each of these admissions was due to respiratory failure, with or without chest infection. A repeat MRI brain scan undertaken on 21 June 2021 demonstrated:

“Evidence of global established cerebral and cerebellar injury, primarily affecting cerebral and cerebellar white matter (with associated cerebral white matter calcification) > thalami and dentate nuclei > the other central grey matter structures. No

specific underlying diagnosis is currently established. AGS is radiologically within the differential, although I note the negative gene panel and some radiological atypical features. The involvement of the thalami, central white matter, corticospinal tracts and perhaps dentate hilae can be seen in Krabbe's disease, but I note the patient is only a carrier of the gene mutation. Probable lactate peaks are shown on SVS but these are small and may reflect current intervening illness. Although a mitochondrial cytopathy remains within the differential, no cystic white matter or striatal necrotic changes are present."

11. On 8 December 2021 J suffered a cardiac arrest, whilst in hospital, which required cardiopulmonary resuscitation for 6 minutes. In March 2022, whole genome sequencing data demonstrated that J suffers from an inherited genetic defect of the NRROS gene. As I have previously stated, this is an extremely rare terminal neurodegenerative genetic condition. Research has revealed that there appear to be no more than 15 documented cases worldwide. Each of those cases follows a very similar trajectory to that I have set out above. What is a particularly distressing feature but, sadly, not unique to this disorder is that the children all seem perfectly well in their first 18 months.
12. J has required 8 admissions to PICU this year. She is colonised with a number of antibiotic-resistant bacteria, including a carbapenemase resistant enterococcus (CPE), an extended spectrum beta lactamase (ESBL) klebsiella and methicillin resistant staphylococcus aureus (MRSA). During the course of this hearing, J was admitted to PICU to enable her parents to come to court. She was discharged to her parents' care at home on the 18th August 2022. Sadly, she was readmitted on 20th August 2022, with repeated apnoeic episodes. A further bacterial infection was discovered though I have been told, by way of update, from Dr W, Consultant Paediatric Intensivist, this does not appear to be significantly compromising her health at the moment and is responsive to one remaining antibiotic.
13. Chest radiographs have demonstrated variable patchy areas of consolidation and collapse affecting both lungs.
14. A great many medical professionals have been involved in considering J's circumstances. To illustrate the breadth of the enquiry, it is helpful to set out the panoply of expertise which has been garnered on J's behalf:

Dr R, Consultant Paediatric Neurologist
Dr W, Consultant Paediatric Intensivist
CS, Junior Sister, PICU
Dr I, Consultant in Paediatric Respiratory Medicine
Dr K, Consultant Clinical Geneticist
Ethics Committee Guidance meeting, December 2021;
Ethics Committee Guidance meeting, 22 May 2022;
Dr P, Consultant Paediatric Neurologist
Dr B, Consultant Paediatrician
Dr J, Consultant Paediatric Intensivist
Professor Stephen Playfor, Consultant Paediatric Intensivist

15. Sadly, the wide gamut of the medical evidence, across this very considerable expertise, has produced a high level of medical consensus, supportive of the Trust's application. Professor Stephen Playfor was instructed, on behalf of the parents, to conduct an overview of J's medical history and to provide an opinion. Though I have no doubt that much hope was invested by the parents in his considerable expertise, Professor Playfor was very clear that mechanical ventilation was not in J's best interests and that the clinical emphasis should be focused on palliative care in the community. Because he was unable to support the parent's case, he was called to give evidence by Ms Victoria Butler-Cole QC, on behalf of J.
16. In common with all the other professionals, Professor Playfor was struck by the expert care and devotion received by J from her parents as well as from the nursing and medical staff. She is repeatedly recorded in statements and in the medical notes as being "*immaculately turned out*". Professor Playfor examined J on the 19th July 2022 and considered a number of video clips taken between 5 and 7 months ago. He describes J as suffering from "*a relentlessly progressive neurodegenerative condition*". He concluded that J had consistent clinical features with and had followed a typical course for NRRS-genetic disorder.
17. Professor Playfor constructs his analysis by reference to the principles identified by the Royal College of Paediatrics and Child Health (RCPCH) published in March 2015: **Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice**. This sets out circumstances under which withholding or withdrawing life-sustaining treatment might be ethically permissible. The RCPCH guidance also clarifies that in the medical context, just as in these legal proceedings, '*the ethical basis for withholding or withdrawing life-supporting therapy (LST) involves consideration of a child's best interests*'. Though the guidance is familiar to practitioners, I propose to summarise it in order to give context to Professor Playfor's conclusions. The RCPCH guidance identifies three paradigm circumstances where limiting treatment should be considered because it is no longer in the child's best interests to continue it, because treatments cannot provide overall benefit. These are as follows:

i. When life is limited in quantity;

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

- a. Brain stem death, as determined by agreed professional criteria appropriately applied.*
- b. Imminent death, where physiological deterioration is occurring irrespective of treatment.*
- c. Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit. (my emphasis)*

ii. When life is limited in quality;

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

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

iii. ***Informed competent refusal of treatment.***

18. Professor Playfor considered that J's case fulfilled Sections 1(C) and 2(C) as I have highlighted above. He also thought it '*highly likely*' that J's circumstances accord with the criteria in Section 2(A). I agree with each of these. This also reflects the medical consensus. However, it is important to identify that there have been varying shades of opinion, amongst the specialists as to the nature and extent of J's capacity to experience pain or pleasure.
19. Miss Nageena Khalique QC, on behalf of the Applicant Trust, submits, the fundamental ethical obligation of the medical profession is "*to do no harm*". It follows that intrusive intervention which is both burdensome to the patient and medically futile (in the sense that it achieves no positives) ultimately becomes harmful. The Court cannot make a declaration compelling a treating clinician to undertake that which is identifiably unethical. It is important for me to emphasise that this analysis has not been advanced in these stark terms by the doctors. Each of the medical professionals, from whom I have heard, has enormous respect for and sympathy with these parents. Their language has been unfailingly sensitive. The familiarity of both parents with the medical issues reflects not only their deep commitment to do anything humanly possible for their daughter but also the time and effort expended by the medical staff in explaining what the frequently complex medical issues are. All this said, it is important not to hide from the stark reality of the doctors sensitively expressed medical conclusions.
20. Professor Playfor summarises his conclusion in his substantive report thus:

"[J] is a 6-year-old girl who suffers from a relentlessly progressive neurodegenerative condition due to an inherited genetic defect of the Negative Regulator of Reactive Oxygen Species (NRROS) gene. There is no treatment for this condition, and she is, sadly, going to lead a very short life.

[J] has lost the ability to stand, control her own body or feed herself. She is entirely dependent on others for care. She has lost the ability to communicate and, in my opinion, has lost the ability to be aware of, and to interact consciously with, her family and the environment around her. J suffers from frequent seizures and increasingly burdensome episodes of respiratory

insufficiency which have led to her being admitted to PICU for periods of mechanical ventilation around 19 times since January 2021.

I have seen no evidence to suggest that J experiences benefit from life, and it is my opinion that she most likely still experiences some burden from therapeutic interventions. It is my opinion that mechanical ventilation is not in J's best interests and that the clinical emphasis should be shifted to the provision of palliative care in the community to optimise J's comfort and dignity."

J's level of responsiveness and her capacity to experience pain and/or pleasure

21. Professor Playfor was in no doubt that J is incrementally losing her capacity to demonstrate a response to painful stimulation. He considered that the limited responses that he was able to observe and which the parents described, "*most likely represent J's vestigial response to painful stimulation, as over time her ability to cough and grimace have been lost*". In his evidence, he expressed that whilst much of J's awareness of her surroundings has now been lost, she retained a basic and 'residual' capacity to experience pain. He did not consider that automatically permitted the possibility of pleasure as a logical correlative. Indeed, he considered it unlikely that J could experience pleasure. As I have foreshadowed, there were different perspectives on this point, although the differences reflect the diversity of clinical expertise rather than any disagreement. Broadly similar opinions are arrived at through the filter of the individual discipline. Miss Khalique has summarised these in her helpful and detailed position statement, from which I can conveniently draw.
22. The family, as is so often the case, has different perspectives from the medical professionals concerning J's response to and perception of the environment around her. These were noted by the Ethics Advisory Group which met on two occasions, the most recent being May 2022. The records contain the following observations:

"Observations by all medical professionals who have seen J in the hospital setting have concluded that she does not respond to the world around her. She gives no indication of feeling pain, but this is not certain, and that she is feeling pain but not able to relate that cannot be ruled out. The best-case scenario...is that she is incapable of experiencing anything including pleasure or pain. The worst-case scenario... is that she feels pain but that this cannot be detected by all of the usual mechanisms as she appears to give no response at all. In the best-case scenario, it seems likely that it is not in her best interests to continue to admit her to hospital for resuscitation, as to do so maintains her in an ever more increasing frequency of admissions that are now arguably prolonging the dying process of her brain. In the worst-case scenario, such admissions are likely to cause suffering that is not outweighed by positive benefits, such as being able to enjoy life. It is not clear that LTV significantly changes the balance of burdens

and benefits, and therefore consideration of her best interests, because it is not clear that she has the capacity to perceive any benefits from living at all.

Community nurses as well as family members. [J] is more responsive at home, though this appear to be at a low level and is inconsistent. [J] has had to spend more and more time in hospital over the last 18 months, so her opportunities for the more positive experience of home life have diminished. Further, if [J] is more responsive and happy at home, she could be aware of a change in her environment when she is in hospital which is likely to be to her emotional detriment. The frequent hospital admissions (probably 20/30 miles from her home, and, when there is insufficient capacity at BCH, a longer distance) is very disruptive to family life not only for [J] but her sibling too.”

23. In addition to the expert instructed on behalf of the parents, the Trust also commissioned second opinions from external clinicians who were provided with the video clips and photographs presented by the parents in July and on 12 August 2022, to illustrate their perception of J’s ability to experience pleasure, pain and suffering and/or her responsiveness.

“Dr B (Royal Stoke Hospital) considered J’s level of awareness in September 2021:

- a) *Parents showed me a video from that time celebrating her birthdays... I could not see any spontaneous purposeful movement. I noticed she needed support for her head. There might have been a brief eye movement but no recognition and no communication;*
- b) *During my observation and examination...she had periods of wakefulness and eye opening but was not able to fix and follow purposefully. Mother had the impression that occasionally when she wakes, she looks at her but I am not so sure of this myself. She did not make any purposeful movement of her hands and feet;*
- c) *Parents said June/July she occasionally had a weak smile, but I did not witness any*
- d) *Her ability to interact with her environment and experience pleasure is minimal. The burden of invasive ventilation would be significant.*

Dr P’s (Addenbrooke’s Hospital) observations as to [J’s] responsiveness in April 2022:

- a) *During the videos and also in my physical examination, firstly I noticed that she has sever developmental delay. [J] was not able to fix and follow, swallow or move her limb independently. In the bed as I lifted her off she had complete absence of any neck or truncal control*

- b) *She has a conjugate gaze, but the movements rove and she neither fixed or followed on me, or appeared to do it with you during the video footage when she was happy*
- c) *Even when you cannot see [J] cry or wince, procedures that are painful for other children e.g. blood tests/cannulation will be painful for her.*

Dr J (GOSH) previously expressed an opinion as to [J's] experiences on 24 May 2022:

- a) *[J] seems to have no purposeful interaction with her environment, so it is impossible to determine if she experiences any pleasure or comfort. It is equally unclear how she may experience pain or, indeed, be harmed by interventions other than knowing they would be painful in children who could communicate this;*
- b) *On the day I visited...[J] was brought in as an emergency due to central apnoeas and possible infection and had been placed on mechanical ventilation. She ...seemed to have no interaction with the environment, including venepuncture... [J's] parents... accept that she has very limited interaction with the world, even at her best.*

The court will also note the direct observations made by Ms Ashton (the Guardian) regarding [J's] responsiveness, which accords with some of the observations made by [J's] parents:

- a) *I can also understand their view that on a good day [J] is capable of hearing and responding to them call her name with some eye movements. This is what I believe I saw during my most recent video call;*
- b) *[I] hold the view that [J], who may have the lowest level of awareness of her surroundings, receiving love and care from her mother, father brother and extended family is of benefit to her;*
- c) *Sadly, I could not detect any sign of [J] being able to derive any experience of this herself. The parents showed to me a significant number of photos and videos they have documented of [J], within some of these she demonstrated some ability to engage with those around her, expressing engagement to varying degrees. However, none date within the last 6 months: the timeframe within which her medical needs are said to have increased and her experience of life deteriorated;*

- d) *An ability to experience pain without expressing this remains a possibility for [J], particularly when her needs are acute and lifesaving treatment is required*
- e) *It is the parents' fervent belief that [J] does experience pleasure from the love and care she receives...My observations of [J] via videocall, seeming to respond to her parents with her eyes could very reasonably be interpreted as an indication that [J] does retain the ability to sense their presence and respond to them. They also state...that [J] experiences pain and discomfort from the process of being 'bagged' en-route to hospital in emergency situations, which are increasing in frequency;*
- f) *Remaining open to the possibility that [J] is able to derive benefit from the love and care of her family, it must also then be considered that conversely, she experiences the pain and burdens associated with the continuation of treatments...I would expect that the sensation of being unable to breathe for herself, having her airways cleared and the unfamiliarity of the hospital ward make for frightening and traumatic experiences;*
- g) *I worry for [J] that experiencing the pain/discomfort and trauma associated with the deterioration of her medical condition is likely to become more acute...her condition is worsening and therefore the benefits she gains from being surrounded by the love and care of family has reduced and will continue to reduce further.*

In addition, the court will note family friend, Ms Linda Fleming's observations of [J] at home, specifically that she has "seen [J] follow her parents with her eyes, following the movement of fingers being clicked together, on occasion smiling when being tickled etc. I've seen her to appear to be settled and relaxed at these times"

*The Trust's clinicians have considered these comments as well as the video and photographic evidence alongside their own observations but do not share the parents' view as to [J's] responsiveness. **Dr T** states that [J's] neurological condition is such that "she lacks awareness of her surroundings".*

Further, the clinical team believe she is unable to express her discomfort or distress from treatment whilst being mechanically ventilated and shows no consistent interaction or recognition to her parents or carers' voice, touch or surroundings and conclude that "she does not react or relate with the outside world".

Dr T concludes that “in my opinion J no longer has the human instinct and desire to survive”. He will assist the court as to the clinical team’s views regarding the photographic and video evidence disclosed to date (and on 12 August 2022) in oral evidence.

Junior Sister CS gives an overview of the nurses’ observations as well as her own “I have not witnessed any purposeful movement or interaction from J. She blinks her eyes and has short dystonic like twitches in her limbs however nothing anti-gravity or purposeful. I have not witnessed any facial expressions or behaviour changes to indicate any potential communication with her caregivers be that her family or nursing team member...I note no difference in J’s awareness of her surroundings whether she is in her bed or chair, or to being moved/ hoisted between the two”

24. Having read and listened to all the evidence on this important point, I consider that Professor Playfor encapsulates the most accurate description of J’s awareness when he describes her as probably continuing to experience a “*residual level of pain*”. Dr R, the neurologist, was clear that the damage to the cerebral cortex was such that the messages did not get through to the brain. This was further supported by the clear brain atrophy revealed on the MRI scan and the consistently abnormal EEG confirming encephalopathy and epileptic activity, additional to that seen in the extensive seizures, some of which last more than an entire day. Nonetheless, the epilepsy, the apnoea, the desaturations were in Dr R’s view, likely to cause some remaining physical discomfort.
25. The father (F) believed that J has a greater level of awareness than the doctors truly understand. He impressed upon me that there is a bond between parent and child which gives the parents an advantage in understanding nuances of behaviours that the professionals might not otherwise recognise. F did not, in any way, disavow J’s manifest deterioration. His simple point, expressed with conviction, is that J is not as unaware of her surroundings as the doctors believe. To illustrate this, he tells me that when J is at home, she experiences markedly fewer convulsions. This, he says, signals her capacity to respond to a quieter more private environment, surrounded only by love and care from her parents and her brother. There is nothing to gainsay this.
26. Whilst I may not always accept the accuracy of F’s observations, he has impressed me as a highly moral and honest man. I am prepared to accept that J suffers fewer convulsions at home, as F describes, and most likely for the reasons he expresses. The wider evidence is not consistent with this but neither do I regard it as being irreconcilable with it. It has been noted that J shows no response to instances of upheaval in ICU and shows no pain with cannulation. But I am prepared to permit of the possibility that along with the capacity for residual pain, there may well be a residual capacity for an experience of tranquillity and human affection that, within the limits of what J is able to experience, can accurately be described as pleasure. In her evidence, the mother (M) whilst kind and polite to all those who have assisted her daughter, described a level of awareness that was, in my judgement, ultimately an expression of her hope and aspiration but was jarringly irreconcilable with the broader evidential picture, including that given by F.

27. I should also record that the Cafcass officer, having visited J with her parents, considered that J had some awareness of her parents' presence in a manner that she experienced as comforting. The Cafcass officer properly volunteered that she could not root this in any evidence other than to describe an essentially primal connection (my phrase, not hers). I consider that she was entirely right to raise this and in precisely the way she did.
28. J, her parents, and the paternal grandparents came to the UK in June 2016. They came as Syrian refugees under the government's 'Syrian Vulnerable Persons Resettlement Scheme'. Neither spoke any English at that stage. The English they have learned has been largely in the hospital environment. The couple's son (A) was born in their first year here in the UK. He is a lively, happy boy who plays gregariously and who is very fond of his sister.
29. In his evidence, F told me, with no hint of self-pity merely as a statement of fact, that he and his family have had *'hard lives'*. They were compelled to leave their home country, Syria, to which F says he will never return. F told me that his experience in transit for 2 years in Lebanon was, if anything, worse than Syria. He described experience of racial hatred and crude discrimination. He told me that his experience of the UK, notwithstanding all that has happened, has been a positive one.
30. The family is supported by an unpaid volunteer, Mrs F, who is part of a local refugee support group. Mrs F is a retired social worker with 30 years of experience. She describes her role, in a statement provided to the Court, as a *"key friend"* who keeps contact by telephone, WhatsApp videos and home visits, to help the parents when they are struggling practically or emotionally. Mrs F describes the family and their extended family as being very close, loving, and supportive of each other. She describes them as devout Muslims who she perceives as demonstrating *"values of care, compassion, consideration, empathy, and generosity in whatever they can give to others who need help"*. She describes them as an *"open and honest"* couple who strive for independence but who are always genuinely appreciative of any support provided to them. Mrs F says that *"they do their utmost to make a life for themselves in the UK and not to be reliant on the State or outside agencies for support"*. Finally, Mrs F states *"I have a lot of respect for them and consider them to be incredibly brave and resilient despite unimaginable losses"*. To all of the above, I can only state that everything that has been said resonates entirely with what I have seen of this *"incredibly brave and resilient"* family during the course of this case.
31. In language, which is kindly but understated, Mrs F commented that the Trust's view that home ventilation should not commence *"does not sit easily with [the parents] Muslim faith, values and culture"*. F attends Mosque very regularly. Prayer is part of his life. He presented to me as a spiritual man with a love of Allah. This is a family who have had to draw deeply on their faith to survive the many vicissitudes that they have encountered. J was the couple's first-born child. Her name, in Arabic, signals the hope for the future that both parents invested in her. The brutal unfairness of what has happened to J, following everything else this family has experienced, is painful even to consider. Nobody can imagine how they feel. Theirs is a pain which goes beyond human empathy. For reasons with which I need not burden this judgment, I had occasion to notice in court what a close, loving and supportive couple they are. If good parenting can properly be described as a gift, then it is certainly one that has been bestowed upon them. M is a traditionally dressed Muslim woman who is modest

and polite but has strong convictions and an unfailing tenacity when fighting for her family.

32. In his evidence, F told me that to fail to provide home ventilation for J would be ‘haram’... ‘It would be a sin to fail to help her’... ‘it would be murder’. F expressed these views with passion, a degree of anger and with complete conviction. Even though he absorbed and understood the medical evidence, F’s faith drew him in a different direction. It is difficult to capture his thought process but, as I understand it, for him, where life is sustained, even with burden and with no identifiable medical benefit, it permits of hope and prayer and for this reason he believes it to be in J’s best interests. In all this, M both shares and supports her husband’s views.
33. I have deep respect for the parents’ faith and culture. Even though its precepts run in such a starkly contrary direction to the medical evidence, I have given it intensely careful thought. However, there is no prospect here that home ventilation could achieve any medical benefit for J. Relatively little may be known about her genetic disorder, but the extent and significance of her neurodegeneration is all too apparent. She is beyond treatment that can make her ‘better’. From this perspective, a decision not to provide home ventilation cannot be equated with a decision “not to help” J, which F described as the Muslim obligation. She is beyond medical help, but she is not beyond physical burden. Ultimately, surveying the broad canvas of what could contribute to an understanding of J’s ‘best interests’, it is the impossibility of reconciling burdensome intervention with treatment that is ultimately futile, that weighs most heavily. J’s life as a human being has unique and intrinsic value, not only because she is J, but because she is a human being and remains so, even when she becomes, as she is likely to do, entirely beyond pain. Her entitlement to protection of her personal autonomy also must be factored into the fabric of those issues that illuminate where her ‘best interests’ lie. *In North London Clinical Commissioning Group v GU*, [2021] EWCOP 59, I observed the following:

“Though it is an ambitious objective to seek to draw from the above texts, drafted in differing jurisdictions and in a variety of contexts, unifying principles underpinning the concept of human dignity, there is a striking thematic consistency. The following is a non-exhaustive summary of what emerges:

- i. Firstly, human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition;*
- ii. an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being;*
- iii. human dignity should not be regarded merely as a facet of human rights but as the foundation for them. Logically, it both establishes and substantiates the construction of human rights;*

- iv. *thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority;*
- v. *the inherent dignity of a human being imposes an obligation on the State actively to protect the dignity of all human beings. This involves guaranteeing respect for human integrity, fundamental rights and freedoms. Axiomatically, this prescribes the avoidance of discrimination;*
- vi. *compliance with these principles may result in legitimately diverging opinions as to how best to preserve or promote human dignity, but it does not alter the nature of it nor will it ever obviate the need for rigorous enquiry.”*

34. The leading and clearest iteration of the law remains that in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67:

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

“[45] Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests' test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account

because they are a component in making the choice which is right for him as an individual human being.” (per Baroness Hale)

35. J’s rights, protected by the European Convention on Human Rights, are engaged. In the present context, the relevant rights are established by Article 2 (the right to life), Article 3 (protection from inhuman or degrading treatment) and Article 8 (the right to respect for a private and family life). As the ECtHR recognised in Burke v UK [2006] (App 19807/06), [2006] ECHR 1212:

“the presumption of domestic law is strongly in favour of prolonging life where possible, which accords with the spirit of the Convention (see also its findings as to the compatibility of domestic law with Article 2 in Glass v. the United Kingdom, no. 61827/00, § 75, ECHR 2004-II).”

36. In this context in *Aintree University Hospitals NHS Foundation Trust v James* (supra) at [22], per Baroness Hale highlighted the following, which seems to me to be particularly apposite in this case:

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

37. These sentiments were re-stated in *An NHS Trust v Y* [2018] UKSC 46 at [92], Lady Black delivering the judgment of the court stated:

“Permeating the determination of the issue that arises in this case must be a full recognition of the value of human life, and of the respect in which it must be held. No life is to be relinquished easily.”

38. I have revisited the cases of *Fixsler v Manchester University NHS Trust* [2021] EWCA Civ 1018 and *Barts NHS Foundation Trust v Raqeeb & Ors* [2019] EWHC 2530 (Fam). I have given a good deal of thought to McDonald J’s judgment in *Raqeeb*. The following passage, in that judgment, is significant:

“The court must face head on the question of whether it can be said that the continuation of life sustaining treatment is in Tafida’s best interests. There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child’s and mankind’s desire to survive. In this context, I do not discount the grave matters prayed in aid by the Trust. However, the law that I must apply is clear and requires that the best interests

decision be arrived at by a careful and balanced evaluation of all of the factors that I have discussed in the foregoing paragraphs. Having undertaken that balance, in circumstances where, whilst minimally aware, moribund and totally reliant on others, Tafida is not in pain and medically stable; where the burden of the treatment required to keep her in a minimally conscious state is low; where there is a responsible body of medical opinion that considers that she can and should be maintained on life support with a view to placing her in a position where she can be cared for at home on ventilation by a loving and dedicated family in the same manner in which a number of children in a similar situation to Tafida are treated in this jurisdiction; where there is a fully detailed and funded care plan to this end; where Tafida can be safely transported to Italy with little or no impact on her welfare; where in this context the continuation of life-sustaining treatment is consistent with the religious and cultural tenets by which Tafida was being raised; where, in the foregoing context, transfer for treatment to Italy is the choice of her parents in the exercise of their parental responsibility and having regard to the sanctity of Tafida's life being of the highest importance, I am satisfied, on a fine balance, that it is in Tafida's best interests for life sustaining treatment to continue. It follows from this conclusion that I am also satisfied, the court having determined the dispute regarding best interests in favour of the treatment being offered to Tafida in Italy, there can be no justification for further interference in Tafida's EU right to receive services pursuant to Art 56."

39. Manifestly, the factual substratum to that case is very different from that which arises here. Indeed, I have never encountered a case where the facts of *Raqeeb* have arisen. J probably experiences a degree of residual pain. Paradoxically, the parents own evidence is highly supportive of that proposition. Moreover, it must be emphasised that J has lost the ability to exercise any control at all over her own body. She is completely and totally dependent for everything on others. She has lost the ability to communicate and has, on any view, only the most limited awareness. Her seizures are highly distressing to watch and are accompanied by increasingly burdensome apnoeic episodes creating significant respiratory distress which have led to the increasing number of admissions to PICU that I have charted above. Sadly, and for all these reasons, I do not consider mechanical ventilation to be in J's best interests.
40. Though they have not been able to contemplate it so far, the time has come for the parents to engage with a palliative care plan that enables the remainder of J's life to be the very best that can be achieved for her. If they can bring themselves to accept this, I can imagine no couple who are better placed to ensure that the end of their daughter's life will be peaceful in a way that reflects the boundless love that they have invested in her.