



Neutral Citation Number: [2022] EWHC 2596 (Fam)

Case No: FD22P00635

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 13/10/2022

Before:

THE HONORABLE MR JUSTICE HAYDEN

Between:

**Great Ormond Street Hospital for Children NHS
Foundation Trust**

Applicant

- and -

(1) A Local Authority

(2) M

(3) J

(A Child, by her Guardian, John Brackenridge)

Respondents

Miss Katie Gollop KC (instructed by **GOSH Legal Team**) for the **Applicant**
Mr Daniel Longe (instructed by the **Local Authority**) for the **First Respondent**
Ms Gemma Taylor KC and Ms Jennifer Kotilaine (instructed by **Hecht Montgomery**) for
the **Second Respondent**
Ms Deborah Bryan (instructed by **Beu Solicitors**, for the hearing on 7th October) for the **Third**
Respondent

Hearing dates: 5th and 7th October 2022

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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.

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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.

Approved Judgment**MR JUSTICE HAYDEN:**

1. On the 5th October 2022, the Trust made a “very urgent” application concerning a 5-year-old girl, J, who has complex medical problems. In order that the statements and application could be prepared properly both for the Court and the parties, a request was made that the case should be heard at 3pm. I agreed.
2. In respect of J, the Trust sought the following declarations, which it contended should be granted either on an interim or final basis:
 - i. *It is lawful and in J’s best interests to be provided with non-invasive ventilation, for as long as it is required and tolerated;*
 - ii. *It is not in J’s best interests to receive: invasive mechanical ventilation, deep suctioning, dialysis of any description, inotrope support, manual bagging and chest compressions, and CPR;*
 - iii. *In the event of J being weaned from non-invasive ventilation and her respiratory function deteriorating, it will not be in her best interests to be given further non-invasive ventilation;*
 - iv. *It is lawful and in J’s best interests to receive palliative care including antibiotics (if clinically indicated), light suctioning, analgesia, and sedation.*
3. J is a 5-year-old girl, with a raft of medical challenges in respect of which she has been treated by her local paediatrician, community paediatric team and the GOSH neurology and renal specialty teams. The diagnosis prior to GOSH admission in March 2022 comprised the following:
 - “1. 30-week prematurity;
 2. Generalised developmental delay;
 3. Focal seizures;
 4. Microcephaly;
 5. Quadriplegic cerebral palsy;
 6. PEG-J fed (previously NG fed for several years);
 7. Left sided sensory-neural hearing loss;
 8. Visual impairment, nystagmus, strabismus and hypermetropia;
 9. Failure to thrive;
 10. History of urinary tract infections (UTIs) in infancy;

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11. Resultant USS demonstrating a small, atrophic, scarred right kidney with 5% split function on DMSA scan – normal USS appearances of left kidney with verbally reported normal renal biochemistry;

12. Hypothyroidism;

13. Adrenal insufficiency;

14. MRI scans showing generalised hypomyelination and asymmetric white matter signal abnormalities with cerebellar and thalamic dysplasia;

15. November 2021 PICU admission for Respiratory Syncytial Virus (RSV) infection and hypernatraemic dehydration requiring two days of intubation and ventilation.”

4. To the above, must be added J’s current additional diagnoses:

“1. Chronic kidney disease stage 5 (CKD-5) with oliguria;

2. Fluid overload;

3. Hypertension;

4. Fluid volume and nutritional restriction;

5. Recurrent sepsis -? occult (hidden/unseen) source;

6. Ongoing peri-hepatic collection (fluid collection around the liver);

7. Recent growths of CPC-enterocci and multi-drug resistant pseudomonas (two extremely resistant forms of bacteria) in the respiratory secretions and urine;

8. Deterioration in baseline neurological function, with increasing airway suction requirements for worsening/pooling secretions.”

5. I have seen a list of the medications that J receives addressing a wide gamut of symptoms e.g., hyperthyroidism, anaemia, hypotension, secretion control etc. There are 31 different medications including some administered prophylactically and some to help her sleep.

6. From a nephrology perspective, J was found to have a poorly functioning, small, atrophic right kidney with only 5% function on DMSA scan (dimercapto succinic acid). This may have been the result of urinary tract-associated scarring or a previously existing reflux, nephropathy or dysplasia i.e., abnormal cells in tissue or organs. The left kidney was ‘normal’ on ultrasound scan but was measured at the 5th centile of bipolar length, indicating that it had not undergone any form of compensatory hypertrophy (a type of increased renal growth to make up for one of

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the kidneys functioning poorly). She had however, normal blood pressure, no reports of proteinuria (*excessive protein loss in the urine*) and normal kidney function tests. She was not troubled by urinary infection from this point onwards.

7. Early-life MR brain scans had highlighted abnormalities with hypomyelination, asymmetric white matter abnormalities and dysplasia of the cerebellum and thalamus (*parts of the brain responsible for co-ordination control*). Serial scans over the first few years showed progressive atrophy (*loss of volume/size*) of the brain that did not correlate with external features of neurological deterioration. The collection of neurological features and MR image findings led the neurology team to consider J to have an underlying neuro-genetic disorder. Extensive genetic testing has not found an obvious underlying genetic cause. A homozygous (*means to possess two copies of a gene*) variant of unknown significance (*not sure if it's important or medically relevant*) was found for a gene known as *SDP-1* which has been associated with microcephaly but not the complete picture that J presents. The treating neurology team investigated the use of a rapid triome sequence which analyses the DNA of J and both of her parents to look at areas of key difference.
8. In early life, although significant, her condition was not thought to be obviously progressive. J was taken to her local Paediatric Emergency Department, in February 2022, in a state of extremis, characterised by hypovolaemic (*low blood and effective circulation volume*) and septic shock. She suffered a brief cardio-respiratory arrest. She suffered from severe metabolic acidosis, end-organ hypo-perfusion and resistant hypotension requiring triple inotropes and intravenous steroid support. During the initial resuscitation, she had an unrecordable blood pressure for over 30 minutes, signifying the severe extent of the cardiovascular insult.
9. J was transferred to the ICU of St Mary's Hospital where she had a further cardio-respiratory arrest. As a result of such a significant cardiovascular and septic event, she suffered organ damage due to compromised blood flow and oxygen delivery to the organs. Her kidneys suffered an injury, technically classified as *AKI stage III* with a severe drop in GFR (*glomerular filtration rate - meaning kidney function*), rise in serum creatinine levels and reduction in the kidneys' ability to excrete uraemic toxins and freely filtered water. An emergency laparotomy (*surgical procedure where the abdomen is opened to explore what may be happening inside*) performed on the unit, discovered 1000mls of blood within the abdomen (*haemoperitoneum*) in addition to a splenic infarction (*death of spleen tissue*), a laceration to the liver (*a tear in the structure of the liver*) and a perforation of the bowel with associated peritonitis (*infection of the abdominal cavity 2nd to gut bacteria spillage*). The surgical view, at the time, was that this may have been caused by some kind of abdominal blunt force trauma. This presentation remains unexplained and has led to public law Children Act care proceedings.
10. The abdominal fluid was drained, as was a subcapsular liver collection, the aspiration of which fluid cultivated candida albicans (*fungal species*) which was treated with amphotericin. I am told by Dr Wallace, Consultant Paediatric Nephrologist, who prepared an independent report prior to the commencement of proceedings, that fungal peritoneal growths can be associated with chronic damage to the peritoneal lining, which has very significant resonance in terms of potential treatment, to which I shall return below.

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11. During the most acute phase of J's PICU admission, she experienced a specialised type of blood dialysis known as CVVHF (continuous veno-venous haemofiltration) which is used commonly in intensive care settings where there is hope that the situation will be temporary, with recovery of renal function to a sufficient degree that this therapy can be discontinued. It is not a long-term therapy, given its slow, continuous nature, the time taken and the anticoagulation requirements to prevent the blood from clotting in the circuit. It is however seen as a very efficient ICU-based therapy, compared with standard haemodialysis, given its slower, gentler nature with less cardiovascular side-effects. In J's case it was used initially to help normalise her severe acidosis and ultimately to address her AKI III, and to remove fluid and toxins that her kidneys were not able to alone.
12. It is important to emphasise that this treatment is effectively a bridging process when there is a real prospect of renal recovery. It can have no effective utility in any other context. The common complications arising from this therapy are clotting of the circuit - leading to anaemia, increased blood transfusion requirement, thrombocytopenia (low blood platelets with increased bleeding and thrombosis risk) and the complications arising from the central venous vascular access itself i.e., line thrombosis, migration, occlusion and line-associated sepsis.
13. J required this "*slow, continuous form of haemodialysis*", as Dr Wallace describes it, for a period of approximately six weeks before enough urine output returned following the resolution of the acute stages of the kidney injury. On stopping CVVHF, there was an immediate deterioration in her kidney function, signifying that the underlying kidney tissue had been permanently damaged and that she now had CKD (*chronic kidney disease*). During the PICU stay, she had also been troubled with persistent infection, characterised by fever, altered physiological observations and high inflammatory blood markers.
14. J had Klebsiella (*bacterial species*) grown from her endotracheal tube secretions and blood cultures were positive for parainfluenza type III (*viral species*). Whilst on the haemofilter, she suffered a period of DIC (disseminated intravascular coagulation) requiring the transfusion of many blood products. She was unable to tolerate any enteral feeding for most of this time and required intravenous nutrition (TPN). J was transferred to the PICU at GOSH in March 2022 for the ongoing management of her chronic kidney disease and continuing concerns regarding the recurring/non-resolving nature of her septic episodes. Prior to transfer, anxiety had been raised about the potential for her left kidney to be a focus of this infection.
15. Ultrasound imaging on transfer had shown the left kidney to be large and echogenic (*bright appearances on ultrasound*) and a CT scan of the abdomen, on 4th March 2022, suggested that the kidney had abnormal heterogenous enhancement with hypo-attenuated areas (*a patchy appearance with dull areas spread throughout the tissue*) that may suggest pyelonephritis (*infection of the kidney tissue*). At the time of transfer to GOSH, her blood urea level was 20mmol/l with a creatinine of 370µmol/l (*J would be expected to have a creatinine level of around 20-50µmol/l in the absence of kidney impairment*). She was oliguric (*low urine output*) producing between 0.3 to 1.2mls/kg/hr with the assistance of regular diuretic medication (*drugs to enhance the production of urine*). She was 11.4Kg on transfer to GOSH. At GOSH, she has continued to have apparent prolonged periods of clinical infection that have not been

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confirmed by positive blood cultures but have responded to antibiotic/antifungal medications.

16. On stopping these prolonged, broad-spectrum antimicrobials, J again demonstrated clinical features suggestive of ongoing occult (*hidden/unseen*) infection within days, necessitating the restart of the therapies. Ultrasound and CT scans have shown the persistence of a peri-hepatic (*surrounding the liver*) fluid collection, but radiology-guided aspiration did not isolate any further bacterial/fungal species, although she was treated with IV meropenem at the time which can prevent successful growths in the laboratory.
17. The infectious diseases team has extensively investigated J, looking for occult sources of infection in bone and soft tissue but none have been found. Her CKD has been managed with the use of three diuretic medications, targeting different segments of the nephron, four antihypertensives, phosphate binders and Vitamin D analogues to address her mineral bone disease. As I noted above, she is currently requiring thirty different daily medications. She is still nutritionally, and fluid restricted to 400mls/m²/per day (insensible losses) due to her oliguria, volume overload and hypertension.
18. It is important to highlight that J has required three further admissions to PICU, for respiratory support due to infections and aspiration of secretions, during the last 6 months. From July 2022, the nursing and medical staff have observed a decline in J's overall level of functioning and interaction with the world. They had known J as a lively and engaging personality with a sense of fun and a "cheeky smile". She had been able to interact and explore by means of a rudimentary grasp in her left hand. She was also able to communicate her wishes by vigorous responsive head nods and vocalisations. J delighted in sensory exploration. She is now markedly less alert with little spontaneous eye opening or smiling. The nurses describe her as having "*lost so much*" over the last few months and steadily and slowly become "*a completely different child*".
19. Dr Wallace puts the above in clinical context,

"There has been a definite deterioration in her upper airway secretion control which may reflect changes in her airway/pharyngeal tone and ability to cough effectively. This has resulted in her most recent admission to PICU and the ward staff reported having to provide almost continuous airway suction. They have noted a general lack of response when this is now performed compared to previously when she would resist and gag at the suction catheters. She has suffered profound and prolonged desaturation because of these obstructing secretions. Ward staff report that she is recently "borderline unresponsive" to routine observations and does not respond to the fingerprick blood sugar testing.

*Such is the continuous need for airway and chest management, the general physiotherapy requirements have taken less precedence given time and resource constraints. **Ward staff have reported distress at the amount of suctioning they must***

give throughout 24 hours, interfering with her rest and sleep. Staff members have questioned the utility of doing this and are concerned that J is no longer able to communicate her pain/distress at this continuous, invasive suctioning.” (my emphasis)

20. Miss Katie Gollop KC, who appears on behalf of the Applicants, summarises that which I have set out above thus: *“J’s organs are now failing and there is no prospect of recovery. J cannot maintain her airway and keeping it clear requires deep suctioning. Suctioning is painful and invasive”*. The neurological evidence indicates that the deep suctioning causes distress, which though it cannot be communicated, is revealed by other clinical indicators such as increased heart rate. Miss Gollop continues *“those treating J are unanimously of the view that the focus should now be on maximising her comfort and minimising treatment that is burdensome and unpleasant”*.
21. The hearing in the late afternoon of the 5th October 2022, proved to be unsatisfactory for a number of reasons. It took place against a backdrop in which J had become increasingly unstable and GOSH were concerned that, absent a contrary declaration from this Court, they might feel legally obligated to move her to mechanical ventilation, notwithstanding the clear consensus that that would not be in her medical interests.
22. I was not, ultimately, on the 5th October 2022, prepared to grant the declarations sought on either a final or interim basis. Though J’s mother (M), had a barrister instructed on her behalf, she had not, in my judgement, had sufficient opportunity to discuss the issues with him. On that day, M did not feel able to participate, at all, in the Court process which, because it was hastily convened, for the reasons discussed above, was conducted on a video conferencing platform. M did not feel able to appear on screen.
23. J’s father (F) has not played a significant role in his daughter’s life, though there was a period when he exercised contact, intermittently. He is aware of the care proceedings but, apparently has not been joined as a party. He is not named on J’s birth certificate and does not hold parental responsibility. He had not been informed of the application before this Court. Inevitably, none of the professionals knew what his views might be. Though effort had been made to contact him, it had not been robust. There had been a misapprehension that because F did not have a Parental Responsibility Order, the obligation to contact him was lesser. It is not. In any event, an invidious situation had been generated in which it seemed I would have to resolve these serious questions without being able to hear from M herself. Additionally, as I indicated to Miss Gollop, Dr Wallace had not been provided with the up-to-date neurological evidence and the neurologist was not available to give evidence.
24. It is also important to signal that whilst hearings via video conferencing platforms were proportionate and appropriate within the context of the civil restrictions of the pandemic, they frequently represent a ‘second best’ in terms of quality of hearing. Manifestly, when the Court is considering issues of this gravity, it is essential to harness the best that is available. Generally, indeed, almost without exception, family members have preferred to come to the courtroom. These hearings will invariably

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involve some medical witnesses giving evidence via video link, but it will now rarely, if ever, be appropriate for the application to be heard entirely remotely.

25. Finally, this application was made late in the afternoon. This only serves to put all involved under additional stress. Whilst I understand the high level of professional concern and the background of the case, I considered a period of reflection, for all involved, was very strongly indicated. This is not intended as, nor should it be taken to be, a criticism of the Trust. Nonetheless, it is very important that parties making applications of this kind think extremely carefully about the timing of the application, its impact on the individuals involved, and the inherent risk to the quality of the evidence where it is garnered in haste. On the 5th October, Mr Day appeared on behalf of M. Whilst he was, as I would have expected, entirely faithful to his instructions, he sensitively intimated that M's thinking about these intensely difficult decisions remained fluid.
26. In the light of all the above concerns, I adjourned the case until the 7th October. I made various directions and received a further statement from Dr K, Consultant in Paediatric Palliative Medicine. Dr K met with M on the morning of the 6th October (i.e., very shortly after the hearing). I record the following from her statement, not merely because it explains the evolution of the case, but because I consider it captures a model of sensitive good practice:

“On the morning of 06/10/2022, I reviewed J on the Paediatric Intensive Care Unit (“PICU”) as part of the Palliative Care ward round. I arrived on PICU with [AJ], Clinical Nurse Specialist, and when we arrived J’s sister [R] and her maternal aunt [T] were with her. Whilst I was reviewing J, [M] arrived at the bedside and asked if she could speak to me separately outside. I took [M] to the small meeting room on PICU and we sat down. [M] said that she had reached a decision, and asked if I could I guess what it was? I asked her if it would be easier for her if I said out loud what I thought she was thinking, rather than her having to say it herself. She nodded. I said I thought she had made the bravest and most unselfish decision she will have to make in her life. [M] nodded and said, “she is tired [Dr K], she is tired” (referring to J). [M] said she could not put J through an intubation to be ventilated. If she did, it would be doing it for herself rather than for J’s benefit.

[M] explained to me that she had come to the conclusion that it is not in J’s best interests for her to be intubated or for her to be resuscitated if she has a cardiac arrest. [M] explained that she recognised that J’s body was not able to maintain stability, and that J had that needed intense, invasive, distressing treatment yesterday morning to recover from her profound desaturation (whilst on PICU on 05/10/2022 J had desaturated, with her oxygen levels down to 31%). [M] said she also had noted that J’s blood pressure was low today.”

27. Dr K and M discussed, in detail, the decisions M was now making. In particular, Dr K appreciated that M had “needed to absorb for herself” the extent to which J was

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“tiring”. That word has been used with some frequency by a variety of professionals. Intubation and invasive ventilation, in these circumstances, overwhelms the autonomy of the patient. In effect, the machinery forces the patient to run when she may prefer to walk or rest. Imposition of this burden requires a prospect of ultimate benefit, here, there is none. Dr K and M agreed that current non-invasive ventilation via face mask would continue as J appears still to be benefitting from it. They agreed that superficial suctioning of J’s secretions in and around her mouth would continue but deep suctioning into her throat, would cease. The following plan was agreed:

- i. *That J should not be intubated and ventilated (i.e., invasive ventilation);*
- ii. *That she should not receive manual bagging (i.e., manual ventilation via a facemask and bag) or chest compressions in the event that J has a profound desaturation or cardiorespiratory arrest; and*
- iii. *That she should not receive deep suctioning (as [M] recognised that this is distressing for J).*

28. M emphasised that she wanted to focus on spending as much time with J as possible at the end of her life. GOSH treats very sick children from all over the UK and from abroad. Inevitably, given the very serious conditions those children suffer from, the hospital has become skilled and sensitive to facilitating end of life palliative care which goes far beyond the purely medical. J’s family will be supported by a psychology team and arrangements have been put in place to ensure that these last memories are precious ones. M has been particularly insistent that J has pain relief and “calming medications” as and when she needs them. She is anxious to ensure that J is not scared or in pain. A symptom management plan to address difficult or laboured breathing, agitation, seizures, and secretions has been devised. There will be regular reviews and ongoing discussions. J’s condition remains grave and fragile, and her episodes of hypotension continue.
29. At the hearing on the 7th October 2022, I was told by Ms Taylor KC, now instructed on behalf of M, that though M was agreeing to the Trusts’ proposals, she did not want to appear on screen (Counsel was in the courtroom, Ms Taylor’s junior counsel, Ms Kotilaine and solicitors, appeared ‘remotely’ from the hospital). Mr Longe, the advocate for the Local Authority, told me that despite what I accept were extensive efforts, it had still not been possible to trace the father. He did not respond to the email address he had given, nor answer his mobile telephone. The social worker visited his address but there were no signs that he was living there.
30. Rather to my surprise, M did appear on the video link. She listened carefully, though she made no comment. I told her that I recognised the dark hours of anxious thought that she had given to this application. The evidence strongly supports M’s decision. Her focus is entirely on her daughter. Nonetheless, as I explained to her, we none of us know how we would react in M’s situation. Grief can easily ambush sound judgement and hope can sometimes flourish in even the most barren of soil. Whatever course M took, whether to contest or to consent to the applications, would have been equally respected by this Court.

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31. Cases of this kind properly attract great public interest. It requires to be emphasised and to be understood that the overwhelming majority of these difficult decisions are taken by doctors and families, moving forward together by agreement. Recourse to the Court is rare. It is, however, uncommon for agreement to be reached once a case has commenced litigation. In that respect, this case is unusual. I have handed down a judgment for two reasons. Firstly, the transparency of the process requires that once the applications have been placed in the public domain, the outcome should be made known, as well as the underpinning reasons for it. Secondly, protracted litigation at the end of a child's life can be deeply scarring for all involved and where it can be avoided, it should be. It may be that there are lessons here which may have positive resonance in future cases.
32. Counsel have considered what factors may have enabled this case to move forward collaboratively. Before I turn to those matters however, it is important that I record that Ms Taylor properly took time, in her submissions, to emphasise that which M particularly wanted to convey. J is far more than the raft of medical problems that this judgment has inevitably had to focus on. She is an immensely determined personality. M reports that she is "*not a quitter*" and has "*a very strong will*". She has shown resolve to prove others wrong. When it was said that she would not be able grasp things, she found her own unique way to do so. Similarly, when she was assessed as unable to clap, she found her own way to do that too. She has a subtle sense of humour; her smile reveals three dimples on her cheeks. I was told that she loved to give "*high fives*". Though J has received a great deal of love and care from her family, Ms Taylor signals to me, that they wish to emphasise that she has given them a great deal back.
33. It is challenging to distil factors here of wider or more general significance. However, there are a number of facts which it may be helpful to highlight:
 - i. Applications of this nature made late in the day, on short notice, are inherently undesirable. The opportunity to reflect and absorb evidence in this case led to an outcome which is manifestly beneficial to J and in her best interests. Whilst some urgent applications will be inevitable, they can frequently be avoided by careful and sensitive planning;
 - ii. The sensitivity and skill of the doctors and nurses here reflects the reputation of this hospital and its vast experience of these desperately sad cases. Dr K took great care to make herself available to M and to give M space to absorb the extent and significance of her daughter's decline. She also helped M marshal and articulate her thoughts at a time when it was difficult for her to do so. The extracts from Dr K's conversations with M, set out above, are to my mind, a paradigm of good practice;
 - iii. The extant care proceedings meant that M already had her own experienced family lawyers in place, who have greatly assisted her. I have no doubt that has been invaluable and has been a significant factor in achieving this outcome for J and her family. Though such circumstances will rarely arise, it is illustrative of the very considerable benefit to be gained by timely access to independent and impartial lawyers, familiar with the issues and who can help parents navigate them in a way which respects their own parental autonomy. I

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recognise that the restriction on access to legal aid will not always make this possible;

- iv. Allied to (iii) above is the fact that M has been positively enabled to examine, absorb, and reflect upon the evolving evidence and to consider the detail of the palliative options. She has not drifted into perceiving the competing alternatives as a ‘battle’, nor in any way led to misapprehend a change of position on her part as “giving up”;
 - v. The gentle plans of the “memory making” team and the psychological support available clearly has great benefit. It strikes me that such resources might also be utilised in helping parents to evaluate the medical options and particularly so where they do not have access to their own independent lawyers.
34. There are a number of other factors that have been important here but are by no means unique. M has had immensely thoughtful and kind family support. The independent expert, Dr Wallace, provided a report of conspicuous quality. Its thorough and sensitive chronology of J’s deterioration, the careful identification of the escalating and intrusive nature of medical intervention, and the cataloguing of the extent of the medication generated a clearer understanding of J’s present predicament by setting it in the context of her medical history. I have a strong sense that all this was helpful to M as she carefully identified where her daughter’s best interests lay and, unselfishly, distinguished them, as she said, from what she herself would have wanted. I found the care Dr Wallace had taken to paraphrase complex medical language in simple and accessible terms to be very helpful to all concerned and would strongly encourage such practice.
35. For all the above reasons, I have granted the declarations sought by the Trust and in the terms drafted. I should particularly like to thank the Guardian who has also plainly given this case anxious thought.