



Neutral Citation Number: [2021] EWHC 2927 (Fam)

Case No: FD20P00172

IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 27/10/2021

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

Between :

**UNIVERSITY HOSPITALS OF NORTH
MIDLANDS NHS TRUST**

Applicant

- and -

AS

1st Respondent

- and -

M

2nd Respondent

- and -

F

3rd Respondent

Ms Nageena Khalique QC (instructed by **UHNM**) for the **Applicant**
Ms Shabana Jaffar (instructed by **Cafcass Legal**) for the **1st Respondent**
Mr Ian Brownhill (instructed by **Irwin Mitchell**) **2nd Respondent**

Hearing dates: 25th, 26th and 27th October 2021

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.

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This judgment was delivered in private at a hearing conducted remotely. 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.

The Honourable Mr Justice Hayden :

1. The applicant here is a hospital Trust (“the Trust”), which provides in-patient paediatric services including paediatric intensive care. The first respondent is AS, a child now 4 years and 10 months old. AS was first admitted to hospital in or around April 2020. She is currently an inpatient in the paediatric intensive care unit under the care of Dr J, Consultant in Paediatric Intensive Care and his team.
2. The second and third respondents are AS’s parents. The Trust has regular contact with AS’s mother (M). Most of the Trust’s communications about AS’s care have been between M and the clinicians at the hospital.
3. An application, in similar terms to that made here, was made to Lieven J on 25th March 2020. The application in March 2020 did not proceed to a final conclusion because AS’s family moved from Leicester to Stoke on Trent shortly after the hearing and came under the community paediatric and complex care team in Stoke.
4. The following matters fall for determination by the court:
 - i. What treatment is in AS’s best interests (and specifically as to whether the Trust’s proposed care plan (with ceilings of treatment) is in her best interests?
 - ii. Whether a reporting restrictions order in the terms sought by the applicant should be granted, to prevent the identification of her treating clinicians?

Background facts

5. The factual background to this application is set out in Dr J’s witness statement and the statement of Dr T (AS’s previous consultant) with which Dr J agrees. AS suffers from Krabbe Disease, a life-limiting genetic disorder. Life expectancy for most children with the condition is two to five years. Children affected will usually die by the age of two, but a few can survive up to the age of nine.
6. Both doctors have agreed with an outline of AS’s symptoms and co morbidities. These can be conveniently summarised:
 - i. Infantile onset Krabbe Disease;
 - ii. Central Apnoea;
 - iii. Global Developmental Delay;
 - iv. Unable to self-manage oral secretions;
 - v. Gastroesophageal reflux disease;
 - vi. Nasojejunal (“NJ”) feeding;
 - vii. Seizures;
 - viii. Mild Neuromuscular Scoliosis;
 - ix. Dysplastic hips (dislocated left hip and uncovered right hip);

- x. Severe eczema;
 - xi. Allergies milk, peanuts and egg.
7. Infantile onset Krabbe disease was diagnosed in May 2017 when AS was approximately 6 months of age. She presented with abnormal movements, twitching and stiffening of hands and feet, and irritability, and had also lost her prior ability to hold her head upright.
8. Following a number of investigations, a diagnosis of infantile onset Krabbe disease was confirmed. Specifically, AS was found to have low levels of Galactocerebrosidase enzyme and GALC gene mutation, diagnostic indicators of the disease. As noted by Dr T:

“With reference to US National Institutes for Health disease information and Orsini et al., Krabbe disease is caused by a genetic mutation in the GALC gene which leads to the build-up of a toxic fat, psychosine in the brain and other tissues. This build-up causes progressive damage and loss of myelin cells, the protective insulation that allows nerve cells to conduct electrical activity. Destruction of myelin cells manifests as severe progressive neurological symptoms, and leads to severe developmental delay, intractable seizures, muscle weakness, inability to move, deafness and blindness, inability to feed or swallow and inability to breathe”.

9. Krabbe disease is characterised by four stages:
- **Stage I.** Initially appears normal but develops excessive unprovoked crying at a few months of age, feeding difficulties and gastroesophageal reflux;
 - **Stage II.** Characterised by rapid severe neurologic deterioration with abnormal posturing, loss of tendon reflexes, staring episodes and minor muscle spasms, and atrophy of the optic nerve;
 - **Stage III.** Characterised by poor control of temperature and heart rate, blindness, deafness, and seizures;
 - **Stage IV.** Characterised by very low muscle tone and absence of voluntary movement.
10. All agree that AS is now at stage IV. Dr J and his team believe that AS is deteriorating with no prospect of recovery or cure. In March 2020 Dr T considered AS to be somewhere between Stage 3 and Stage 4. Specifically, Dr T states as follows:

“It was always anticipated that AS’s condition would deteriorate and there would be point in AS’s illness that would require difficult and

sensitive discussions regarding ceilings of treatment and whether mechanical ventilation continued to be appropriate; indeed, the team at University Hospitals of Leicester NHS Trust had considered this in its application before the court. Whilst the current team has worked with AS's family with this in mind, we are unanimously of the view that AS is now at the stage where the burdens of treatment, such as more frequent aggressive, distressing and painful interventions are not in her best interests”.

Hospital admissions

11. The admissions have been conveniently summarised by Ms Khalique QC, acting on behalf of the applicant Trust, and are agreed by the parties to be accurate. On 23rd March 2020, Dr T describes AS's clinical status:
 - i. non mobile and cannot sit upright or reposition
 - ii. reduced muscle tone
 - iii. minimal voluntary movement limited to arm and blinking of eyes
 - iv. no verbal communication
 - v. mother interprets expressions as smiling
 - vi. may experience comfort by touch
 - vii. visual and hearing impairment
 - viii. fed through a naso-jejunal tube as she cannot swallow safely
 - ix. frequent suctioning of saliva and secretions pool in mouth/airway
 - x. no cough/gag reflex prone to aspiration and respiratory tract infections
 - xi. seizures/breakthrough seizures requiring medication
 - xii. ability to experience pain and distress
 - xiii. apnoea (unreliable neurological control of breathing/inability to swallow)
 - xiv. profound falls in oxygen levels which require medical intervention
 - xv. variability in temperature control
 - xvi. heart rate instabilities with sudden drops in pulse (bradycardia)
 - xvii. occasionally requires chest compressions (CPR)
 - xviii. CPR given if heart rate does not recover after increased supplemental oxygen and mask ventilation.
12. Dr T also refers to three occasions when AS suffered a cardiac arrest (in April 2019 (this lasted one minute), October 2019 (lasting 40 minutes) December 2019 (lasting two minutes).
13. Dr T and his team concluded that AS's clinical history, more frequent attendances at hospital for increasingly complex health problems, against the known progression of Krabbe disease, pointed strongly towards her being in the terminal phase of her disease:

“In particular, AS' bradycardias, apnoea and temperature instabilities are manifestations of her brain stem dysfunction. As her Krabbe disease progresses, further deterioration in her brain stem function will result

in her breathing or heartbeat to stop completely and sadly she will die. This process is irreversible and medical intervention however aggressive will be futile”.

14. Dr J notes that AS has required ongoing support from the community teams dealing with complex medical cases, palliative care as well as acute paediatric intensive care (PICU) over the past 18 months. He states that in the last few months there has been “*a noticeable progressive decline in AS' condition, in particular, her ability to cope with respiratory viral infections which have required aggressive suctioning of secretions, intubation and ventilation*”.
15. There is a clear step change in AS’s hospital admissions from around May 2021 with increased frequency and length of stay in PICU and/or hospital. These are set out in Dr J’s statement in tabular form and need not be read into this judgment.
16. Significantly, the latest admission to PICU commenced on 5th September 2021 (now 52 days), during which time AS has been intubated for most of the time (in excess of 40 days). This admission followed just four days after the preceding admission of 28 days (between 4th August and 1st September 2021) when AS was also on PICU and intubated. Her admission between 2nd May and 28th June 2021 (53 days) was also to the PICU ward where she was intubated.
17. The key features of the latest admission are as follows:
 - i. worsening secretions, erratic breathing and episodes of apnoea;
 - ii. frequent desaturations (very low blood oxygen levels) despite increased non-invasive ventilation;
 - iii. obstruction of right main bronchus (branch of the trachea) with secretions;
 - iv. an ineffective cough (due to the progression of her disease) and unable to clear her own secretions such that staff felt AS was: “*too weak to clear her own secretions and that she was effectively drowning in her own secretions*”;
 - v. initially AS was not intubated, but required continuous manual bag and mask ventilation (delivered by a member of staff) with very high non-invasive ventilator pressures, very high inhaled oxygen concentration, and lower jaw thrust (a painful procedure forcing jaw forward in order to maintain the patency of airway);
 - vi. very extensive, continuous intervention with physiotherapy and deep suctioning;
 - vii. during these procedures, AS was noted to be very distressed and in significant physical discomfort; the nursing and medical team caring for AS felt that the level of intervention required to maintain her saturations and secretion clearance was causing her almost continuous distress and discomfort;

- viii. the clinical team felt that it was not appropriate to keep AS on a ventilator but in her best interests to provide palliative care to keep her comfortable without any more aggressive and distressing interventions;
 - ix. the family disagreed with the Trust's proposals so the clinical team agreed to intubate AS (because non-invasive ventilation was no longer tenable), on the understanding that resolution of the dispute between the clinical team and AS's family as to what treatment is in AS's best interests would need to be determined by the court;
 - x. AS was intubated on 7th September 2021 and given continuous pain relief and deep sedation using continuous infusions of drugs. As she improved, medication was reduced and AS was extubated on 23rd September 2021;
 - xi. AS's condition remained unstable and despite repeated, aggressive and prolonged physiotherapy and deep suctioning, AS was extubated but requires 24 hour ventilation (and currently remains on PICU).
18. In the view of the clinical team, the following treatments would not be in AS's best interests and should NOT be provided in the event of deterioration following this current admission:
- i. Intubation and mechanical ventilation: unless AS has had sufficient time at home (8 weeks);
 - ii. Chest compressions (CPR) for cardiac arrest: apart from 1 minute to allow cardiac perfusion during this admission or after 8 weeks post discharge
 - iii. Continuous physiotherapy with deep suction (using a suction catheter that reaches the back of the throat) at a frequency and intensity where intubation would normally be indicated,
 - iv. Defibrillation (electric shock) for abnormal heart rhythms: unless during this hospital admission - 1 minute to allow cardiac perfusion or after 8 weeks post discharge,
 - v. Intraosseous access (access to the circulation for fluids and drugs by drilling a needle into the bone marrow, usually at the ends of long bones like the tibia and femur),
 - vi. Drugs used to stimulate the heart or increase blood pressure (drugs such as adrenaline)
19. The wider views of the team are recorded and set out in the papers. They include nursing, physiotherapy and other staff:

PICU consultants

“Mother does not want her to be intubated, but does want her to be kept alive. Long periods of bag/mask ventilation are needed. Has stated where she is unable to tolerate

without intubation or constant bag mask vent. Has tears in her eyes, and expresses discomfort during this.”

*“[AS] is almost continuously drowning in her secretions, and needs constant suction. Has had periods in the past where has been well, has a devoted family, and they try to do as many normal things as possible. Over the past 5-6 months those days have been virtually nil and she has suffered a lot. **Nurses have gone home in tears as they feel they have been made to harm a child against their will.**” (my emphasis)*

“Has had numerous discussions with mother and have great admiration for their devotion. Has asked about potential future therapy with e.g. gene therapy: this has been checked with the team in Manchester who are trialing this. This is only available for siblings of cases at the point of birth, to avoid progression. Mother’s view is that it would stop any further progression. Has been told there will be no intervention in the future which will stop this progression. Feels mother still holds hope that something will come up.”

“[M] has been told repeatedly that there will be a time where the discussions will be had whether the burden of keeping her alive will outweigh the benefit. Currently needs continuous periods of incredibly difficult interventions with no potential for relief. More than happy to try to support her to go home. Intubating her, or prolonged bagging and deep suction, are inappropriate. Not for CPR.”

“This is the unanimous viewpoint of the PIC team. Never seen her smile. Has seen her at peace, at times without distress. No objective signs of expressing pleasure or joy.”

Matron

“Has had many communications with the nurses involved. Runs twice weekly meetings to support her nurses who are struggling with the case. This is an exceptional level of support needed. [M] wanted a core team, but this has not been done as the levels of care which [AS] needs (both medically and emotionally) needs to be shared around. A pending court case also increases anxiety.”

*“**Nurses are very distressed. Needed bagging for 20 hours on admission to try to avoid intubation. They think they are doing the wrong thing...Wondering whether they are putting [AS] through more suffering, for instance after admission had bruises under her chin with chin lifting.**” (my emphasis).*

“No nurses feel she should be intubated. Is being bagged about twice per hour. Over weekend (2 days ago), [M] said to not intubate, but has changed her mind in the past. Feels she is different to how she presented 2 years ago: much more unstable. At the end of life should be in her [M’s] arms.”

“She lies in the bed all the time, doesn’t smile, cries a lot. No eye tracking. At home [M] keeps the other kids away from her as is frightened of her catching an infection. When breath holding is very vacant. Not purposefully looking at you. When watching dvd, no interaction, no tracking, no reactions. No objective way of knowing she enjoys this. No play. Only movement is some side eyeing, then eyes close. Not consistently

associated to any stimulation, this happens of her own accord. When talking can open her eyes.”

“Not a happy child. Anything which is done to her causes distress. If you try to do something nice to her ends up with bagging. Expresses distress by crying and jitters. Never used to cry but this last admission more so.”

“Believes it is cruel to keep on with current therapy of very frequent bagging. No enjoyment in life for her. Should not be intubated: will just go round in circles. Desats not due to secretions, but apnoeas are central. When desats goes grey. No seizures. No coughing. No gag. Significant bradycardias are more and more frequent. No carers at home, has been offered previously. Other kids; youngest 7, oldest 20. Little time for the other children. [F] visits rarely, is looking after the other children.”

20. There have been several medical teams (acute and community based) involved with AS’s care who have provided opinions both prior to and during AS’s admission to hospital. Of particular note is that of Dr Patrick Davies consultant paediatric intensivist. His report is dated 28th September 2021.
21. Dr Davies’ concludes that AS is very severely affected by Krabbe’s disease (with impact on her respiratory, neurology and cardiac function). She also requires clinically assisted nutrition and hydration (CANH). Dr Davies observes as follows in relation to AS’ hospital admissions:

“Today is the 270th day of 2021, and she has been an inpatient for 135 days, exactly 50% of the time. Since the 2nd May (148 days), she has been an inpatient for 107 days (72%). She has had 7 admissions in 2021, ranging from 3 to 57 days long. None of these admissions have been with a serious illness: they have all been with minor variations of her condition. They demonstrate her fragility and inability to cope with the strains of normal life”.

22. Dr Davies refers to The Royal College of Paediatrics and Child Health’s 2015 guidance ***“Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice”*** which considers situations where withholding or withdrawal of life sustaining treatment can apply and concludes that in AS’s case situations 1c, 2a, and 2c could be applied:

(1) **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:

- c. **Inevitable death:** where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit.

(2) **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

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.

23. Dr Davies is clear that AS is succumbing to the progressive and deteriorating nature of Krabbe's disease. In the final analysis, he agrees that ceilings of treatment should be imposed:

- Intubation and mechanical ventilation should only be given if sufficient time at home (8 weeks) has been achieved;
- Chest compressions (CPR) for cardiac arrest may be given:
 - only during hospital admission, for one minute;
 - not during hospital admission, after one minute;
 - not within the first 8 weeks after discharge;
 - only after 8 weeks post discharge, for a reasonable amount of time;
- Continuous physiotherapy with deep suction should not be given if this is at a frequency and intensity where intubation would normally be indicated: this should trigger an end of life plan (unless more than 8 weeks post discharge);
- Defibrillation (electric shock) for abnormal heart rhythms is only suitable after more than 8 weeks post discharge;
- Intraosseous access (to the circulation for fluids and drugs by drilling a needle into the bone marrow) should not be used (with the intravenous route for antibiotics being preferred) but if there is an overriding need for such access, then this discussion should be had with the family at the bedside;
- If drugs are required to stimulate the heart or increase blood pressure (such as adrenaline), this implies multi organ failure. She should not have these drugs and should be allowed a dignified death;
- Tracheostomy is not in her best interests, due to the risk of complications, her neck anatomy, and the ongoing effects;
- Scoliosis surgery is not in her best interests and she is unlikely to survive the hospital admission around this.

24. Though the parties to these proceedings had indicated that they were agreed as to the way forward for AS, I struggled, on my reading of the papers, to identify exactly what the proposed treatment plan was. I was concerned that though the agreed plan purported to contemplate AS returning home, the prevailing medical view appeared to be that AS's treatment was burdensome, distressing and ultimately futile. The treatment plan begins with the following:

- i. Intubation and mechanical ventilation will not be appropriate for [AS] **unless** she has had at least 8 weeks at home.

The plan continues:

- ii. In the event that AS is able to be extubated during this current admission (October 2021) and deteriorates, one further intubation and extubation will be offered.

Later when contemplating continuous physiotherapy and deep suctioning, the plan states that this:

- iii. Will not be appropriate or clinically indicated where the frequency and intensity is such that intubation would normally be indicated.

25. All this struck me as confusing and rather inconsistent. For this reason, I required the parties to attend. Ms Khalique, called the treating Consultant, Dr J to give evidence. In addition to my anxiety as to the coherence of the plan, I was also concerned why it had taken so long for an application to be made to the Court, given that AS was recognised by the professionals "*to be almost continuously drowning in her secretions*". Alarming, it was clear from the records that the nurses felt that they were causing and not alleviating harm.

26. In November 2019, AS was treated as an in-patient at the Trust. She had been transferred there due to the unavailability of a PICU bed at her local NHS Trust. AS's mother, M felt that the care was better. Shortly afterward she moved the entire family to Stoke-on-Trent to ensure that AS would be in the relevant catchment area. By March 2020, the treating hospital (at that time) had been seeking a declaration that it was in AS's best interests for there to be a ceiling on her care. By this it was planned that invasive burdensome and clinically futile treatment would no longer be pursued. I have no doubt that this development strongly influenced the mother to relocate.

27. In March 2020, the world changed for everybody. With lockdown, social distancing, strict limitation on travel and the wearing of masks, respiratory infection reduced to an unprecedentedly low level. For AS this was an entirely unexpected respite and there were a number of months, coinciding with the most restrictive periods of social distancing in which AS was both liberated from the ventilator and, to some degree, from the painful deep suctioning physiotherapy and bag and mask ventilation. This caused the present medical team to hold back on identifying ceilings of treatment and, in particular, whether mechanical ventilation continued to be in AS's best interests. However, when society began to open up again the situation changed for AS. In his statement filed in these proceedings, Dr J records the following:

“AS was admitted to the Trust on 2 May 2021, with increased secretions and appeared not to be tolerating her normal home non-invasive ventilation. She was transferred to the Trust’s PICU and placed on a ventilator to manage her respiratory failure and increased secretions. She was found to have an adenovirus respiratory infection and she spent 53 days on the intensive care unit during which she received invasive ventilation (with a breathing tube placed in her trachea) for 27 days.

During the course of the PICU stay, she was liberated from the ventilator on two occasions but failed to manage without its assistance and had to have the breathing tube replaced and invasive ventilation re-instituted. A third attempt was successful, albeit with an extensive amount of intervention from the nursing and physiotherapy teams carrying out lengthy periods of intrusive and painful deep suctioning, physiotherapy and bag and mask ventilation. With this amount of intervention, she made progress and was transferred to the Paediatric High Dependency Unit (“HDU”) on 24 June 21, and discharged home on 28 June 21.”

28. Unfortunately, AS’s time at home was very brief. She was re-admitted to the Stoke-on-Trent hospital on an emergency basis, on 4th August 2021. She was suffering increasing shortness of breath following a choking episode at home. She was admitted to PICU and discovered to have a rhinovirus respiratory infection. Dr J told me, in evidence, that this virus is relatively mild for most people but significant for a patient as compromised as AS.
29. If the doctors and nurses will forgive me for saying so, I find some of the terminology used in the reports and records occludes rather than illuminates the nature of the treatment. In the August admission it was not necessary to place AS on a ventilator with accompanying sedation. That treatment is described in the reports as “invasive”. I entirely understand why. The extensive use of ventilators during the course of the pandemic, has made it only too clear how intensive such treatment is and the effect it has on patients. However, it was necessary to manage AS’s respiration by many hours of secretion clearance using deep suctioning physiotherapy and bag and mask ventilation. This was undertaken by both the nursing and physiotherapy staff. This treatment causes AS manifest distress and pain. In a different way it is every bit as invasive. It was undertaken by both nursing and physiotherapy staff who were so distressed that they were provided with twice weekly counselling. They considered that extent of the deep suctioning was, or at very least had become, inconsistent with AS’s general well-being. With respect, I agree.
30. A pattern of admission to hospital, extensive distressing treatment and then return home for a short period began again, following AS’s discharge from this episode on the 1st September 2021. This time she was back within days, indeed only 4 days. Her secretions were worsening, she was suffering episodes of apnoea requiring urgent assistance and her breathing was generally erratic. Her oxygen saturations were poor improving, once again, with very extensive and continuous intervention with physiotherapy, deep suctioning, bag and mask. Her right lung was not being inflated,

most probably because of an obstruction of her right main bronchus with secretions. I do not wish to distress the family but equally it is important that AS's experience is properly understood by them. She was, at this time, quite literally drowning in her own secretions.

31. It is clear that there have been conversations with AS's family about end of life care and emergency care planning on every occasion that she has been admitted to PICU. On each occasion the family has been resistant. They not only wished her to receive the treatments that I have described above, they wanted full intensive care including CPR. AS has a life limiting and progressive neurological condition. The consensus medical view is that with the exception of her experience of pain, she now has minimal interpretable responses to sensory input. She faces frequent complications which presents a significant burden on her.
32. When AS has been at home the family has undertaken her care. I have no doubt, from everything I have heard, that AS would like to be at home in a family environment which is manifestly suffused with love for her. That she has achieved all she has is, as everybody acknowledges, in very significant consequence of her family's commitment to her. There is no treatment that can reverse the damage to AS's brain. For some time now it has been clear to the treating clinicians that AS is reaching the natural end of her life. The aggressive treatments no longer achieve any significant period of stability. AS is at risk of sudden and serious deterioration at any point. She is particularly vulnerable to respiratory deterioration secondary to the SARS-CoV-2/Covid-19 pandemic. For many months and certainly since August AS's treatment has been burdensome and futile. Dr J candidly recognised that he had permitted the views of the family to predominate over the needs of his patient. That candour, which is entirely sincere, signals to me that Dr J is not only a highly experienced consultant but a compassionate man with the humility to recognise error.
33. Why this was permitted to happen has been the focus of attention at this hearing. I found the answer to be cogently and insightfully articulated by AS's guardian Ms Helen Ashton. Ms Ashton had visited AS in hospital and spent the afternoon with her and her family. Like Dr J she was struck by the family's commitment to AS. She described them as devoted to her. She is entirely convinced, as am I, that they are straining to do what they perceive to be in AS's best interests, they are also grieving.
34. When the Guardian visited, the mother and AS's sister (R) reported having been awake until 4am, as AS had a bad night. The Guardian took the opportunity to speak with the nursing team, Dr J and with the family. She was able to construct an accurate picture of AS's situation and effectively evaluate the benefits and burdens of the treatment regime. Though she had agreed with the initial treatment plan, the Guardian was really under no misapprehension that AS could not go home. Ms Ashton told me that what she considered had occurred here was that the doctors had "*got lost in the infectious beliefs of the family*" that AS might yet confound them all and achieve some further prolonged period of relatively good health. The warmth of this family's love and the simple, sincerity of their faith is indeed truly infectious.
35. During the course of this hearing it has been necessary to revisit and ultimately redraft the treatment plan in such a way that makes it entirely clear that we are now planning for the end of AS's life, recognising that she will not be able to return home. It is important to achieve clarity on all this mainly so that the family can make arrangements

to enable them to be with AS at the end, whenever that comes. It need hardly be said that this is what AS would want for herself. The redrafted treatment plan, in my judgment, reconnects the obligation for professional honesty with the equally as important and abundant respect for the family.

36. I also heard from Dr R, a Consultant Paediatrician, with a specialism in Paediatric Palliative Care. She told me that the support that AS would now need at home would be greater than the family would be able to deliver, despite their best endeavours. It would also be difficult to provide the necessary professional care in the home. In any event Dr R considered that AS is now too fragile and might not make it home at all.
37. As Mr Brownhill, on the family's behalf, properly emphasised, that the past few days have been a process where it has been possible to agree some significant landmarks in AS's future care. The following are agreed:
- i) not to re-intubate;
 - ii) not to provide cardiac massage and/or CPR;
 - iii) not to use intraosseous access;
 - iv) not to provide a tracheostomy;
 - v) not to administer antibiotics, save for the circumstances set out in the care plan;
 - vi) to continue with clinically assisted nutrition and hydration, enteral feeds and fluids in the circumstances as set out in the care plan.
 - vii) provide non-invasive BiPAP ventilatory support as set out in the care plan;
 - viii) administer any symptom control and/or palliative treatment in accordance with the care plan including relief from distress, pain and suffering and to retain the greatest dignity until such time as her life comes to an end.
38. The two points in contention involve the use of deep suctioning and the parents wish for AS to be returned home. I have already indicated that the evidence underpinning the conclusion that AS cannot go home is compelling. In respect of deep suctioning, Mr Brownhill emphasises that the parents recognise how intrusive and painful it has become. Their point is that it should not be prohibited because circumstances might arise in which it could be beneficial, for a short period. I think that there may be some force in this, though I can not be sure. I have indicated to the parties that I consider it appropriate to add the following to the declaration:

“Nothing in the above should be interpreted as preventing the treating clinicians exercising their professional judgment in respect of AS's care either in an emergency or if the clinical picture were to take an unexpected turn.”

In making this addition I am signalling to the parents that whilst the treatment plan now focuses on keeping AS comfortable at the end of her life, it expressly leaves space for the hope and faith which has sustained this family thus far and will, I am confident, in the days ahead.

39. Ms Khalique has emphasised the important objective of striving to retain AS's "*greatest dignity until such time as her life comes to an end*". To my mind this is the lodestar in the treatment plan. The concept of human dignity is predicated on a universal understanding that human beings possess a unique value which is intrinsic to the human condition; an individual has an inviolable right to be valued, respected and treated ethically, solely because he/she is a human being. 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; thus, the protection of human dignity and the rights that flow therefrom is to be regarded as an indispensable priority.
40. The focus from this point must be on the preservation of AS's dignity and comfort. The views of the family as to how that is achieved will continue to be important though not determinative.
41. The legal framework that the court must apply in cases concerning the provision of medical treatment to children who are not '*Gillick*' competent is well settled. The following key principles can be drawn from the authorities, in particular *In Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33, *R (Burke) v The General Medical Council* [2005] EWCA 1003, *An NHS Trust v MB* [2006] 2 FLR 319, *Wyatt v Portsmouth NHS Trust* [2006] 1 FLR 554, *Kirklees Council v RE and others* [2015] 1 FLR 1316 and *Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust* [2017] EWCA Civ 410:
- i) The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment;
 - ii) The starting point is to consider the matter from the assumed point of view of the patient. The court must ask itself what the patient's attitude to treatment is or would be likely to be;
 - iii) The question for the court is whether, in the best interests of the child patient, a particular decision as to medical treatment should be taken. The term 'best interests' is used in its widest sense, to include every kind of consideration capable of bearing on the decision, this will include, but is not limited to, medical, emotional, sensory and instinctive considerations. The test is not a mathematical one, the court must do the best it can to balance all of the conflicting considerations in a particular case with a view to determining where the final balance lies. Within this context the wise words of Hedley J in *Portsmouth NHS Trust v Wyatt and Wyatt, Southampton NHS Trust Intervening* [2005] 1 FLR 21 should be recalled:

"This case evokes some of the fundamental principles that undergird our humanity. They are not to be found in Acts of Parliament or decisions of the courts but in the deep recesses of the common psyche of humanity whether they be attributed to humanity being created in the image of God or whether it be simply a self-defining ethic of a generally acknowledged humanism."

- iv) In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests;
 - v) There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great;
 - vi) Within this context, the court must consider the nature of the medical treatment in question, what it involves and its prospects of success, including the likely outcome for the patient of that treatment;
 - vii) There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive;
 - viii) Each case is fact specific and will turn entirely on the facts of the particular case;
 - ix) The views and opinions of both the doctors and the parents must be considered. The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment. There is no requirement for the court to evaluate the reasonableness of the parents' case before it embarks upon deciding what is in the child's best interests. In this context, in *An NHS Trust v MB* Holman J, in a passage endorsed by the Court of Appeal in *Re A (A Child)* [2016] EWCA 759, said as follows:

“The views and opinions of both the doctors and the parents must be carefully considered. Where, as in this case, the parents spend a great deal of time with their child, their views may have particular value because they know the patient and how he reacts so well; although the court needs to be mindful that the views of any parents may, very understandably, be coloured by their own emotion or sentiment. It is important to stress that the reference is to the views and opinions of the parents. Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.”
 - x) The views of the child must be considered and be given appropriate weight in light of the child's age and understanding.
42. These principles have been reiterated repeatedly at appellate level. In *Re A (A Child)* the Court of Appeal confirmed once again that, whilst requiring great sensitivity and care of the highest order, the task of the court in cases concerning disputes in respect of the medical treatment of children can be summed up by reference to two paragraphs

from the speech of Baroness Hale in *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, namely:

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

And

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

43. Ultimately, however difficult the law may be to apply, it can be stated simply. The observations of McFarlane LJ in the case of **Yates and Gard v Great Ormond Street Hospital for Children NHS Foundation Trust** [2017] EWCA Civ 410, required no gloss:

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

Conclusion

44. I have identified the passages in the above authorities because they, to my mind, identify the approach to be taken in these cases in a way which permits of absolutely no ambiguity. There is one principle alone which should guide the decision-making process. Its reach is ubiquitous, it applies equally to the parents, the medical profession and the lawyers, namely that the best interests of the child should always prevail. Sometimes, as here, parents may have a different perspective on where a child's best interests may lie. These views are to be respected, considered and evaluated but where they cannot be reconciled with medical opinion, they should never be permitted to occlude the guiding principle. Moreover, as McFarlane LJ emphasises, this has been underlined by the Courts *“again and again”*.
45. As AS's Guardian correctly identified here, the family's infective hope, belief and simple, inspiring faith ultimately distracted the treating clinicians from their central professional responsibility to AS. It is greatly to the credit of Dr J that he recognised that and so readily acknowledged it. Nonetheless, albeit for the best of motives and

driven by compassionate instincts, AS's voice fell quiet at a time when it most needed to be heard. Invasive and distressing treatment, which was not only burdensome and distressing but had become futile, was pursued for far longer than it ought to have been. This was entirely contrary to AS's best interests. I emphasise again that this is not in any way a criticism of the family, who I consider to be impressive in many ways, but it is important to signal that there is a clear professional, and I would add moral obligation, to bring these cases to court immediately where such difference of opinion cannot be resolved. The first and most obvious advantage is that the child will be appointed a Guardian, the conduit for the child's voice to be heard. The importance of that has been underscored in this case, where the Guardian has made such an important and insightful contribution.

46. Having considered the whole spectrum of the evidence, from both family members and medical experts, reviewed the framework of the law and the weight to be afforded to human dignity, I have come to the clear conclusion that the Trust's application, permitting ceilings of treatment, is properly made and I, accordingly, grant the declaration in the terms now drafted.